Case No: NE15C00439

Neutral Citation Number: [2016] EWHC 535 (Fam)
IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Teesside Combined Courts Centre
Middlesbrough

Date: 11/03/2016

Before :

THE HONOURABLE MR. JUSTICE COBB

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Between :

COUNTY DURHAM & DARLINGTON NHS FOUNDATION TRUST	**Applicant**
- and -	
SS (By her Children's Guardian, Anne Hutson) DURHAM COUNTY COUNCIL FS (Father) MS (Mother)	**Respondents**

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Nicholas Stonor QC (instructed by **Capsticks**) for the NHS Trust
James Brown (instructed by **Local Authority Solicitor**) for the Local Authority
Charles Geekie QC (instructed by **Cygnet Law**) for the Children's Guardian
The **father** and **mother** were not represented
and participated in the hearing by telephone from India.

Hearing dates: 10 and 11 March 2016

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Judgment

The Honourable Mr. Justice Cobb :

Introduction

1. SS ("S") is a girl who is 7 years of age. She is profoundly neurologically disabled, with encephalopathy and microcephaly; she has cortical visual impairment, as well as sound sensitivity. She is globally developmentally delayed, suffers from prolonged seizures, and is fed by gastrostomy. She has advanced scoliosis of her spine and subluxation of her hip. She currently receives oxygen supplement by nasal cannula. The unanimous medical opinion in this case is that even with the best care in the world, S remains at significant risk of sudden and unexpected death.

2. Since August 2015, S has been in the care of Durham County Council ("the Local Authority") pursuant to orders made under *Part IV CA 1989*; one of her younger brothers ("G"), aged 4, who has comparable and equally profound disabilities, is also subject to a care order. S and G reside together in foster care. S was born in India to Indian parents; her parents are currently in India with her two other siblings.

3. On the very day, six weeks ago, on which the Family Court Judge in Newcastle-upon-Tyne made final Care Orders in relation to S and G (26 January 2016), S was admitted to hospital with a chest infection. While in hospital, her health rapidly deteriorated. By 3 February 2016, S was in a life-threatening state; the treating clinicians frankly believed that she was at the point of dying.

4. Urgent application was therefore made by the County Durham & Darlington NHS Foundation Trust (hereafter "the Trust") to the Family Division Out-of-Hours duty judge (Roderic Wood J) under the inherent jurisdiction seeking the court's authorisation not to resuscitate S, in the event of further deterioration and/or collapse.

An interim declaration to that effect was granted that night; on the following day, the application was restored by S's father (who by then had obtained representation) for variation of the order, before Mostyn J. At the conclusion of a short hearing, at which evidence was called, a further interim declaration was made, in broadly similar terms to the order made on the previous night (and in the terms set out at §20 below). S's condition fortunately improved, and she was discharged back to foster care on 22 February. She was briefly re-admitted to hospital with further concerns about her breathing last week. As it happens, in the intervening period her brother has separately been admitted to hospital with uncontrollable seizures.

5. In preparation for the final hearing of this application, at the suggestion of S's Guardian, a second opinion was commissioned on the issues arising concerning S from Dr. Karen Horridge, a Consultant Paediatrician with special interest in disability (see paragraphs 23-27 below), and the case has been listed before me over two days for final determination.

6. The Trust is represented at this final hearing by Nicholas Stonor QC; the Local Authority by James Brown; S by her Children's Guardian, Anne Hutson, (who had represented her in the care proceedings) by Charles Geekie QC. S's parents are currently in India. They have been provided with all of the relevant evidence (sent by secure e-mail) but have not filed any evidence of their own. They have dispensed with the services of their solicitor and have represented themselves before me, participating by telephone over the two days. I have read the relevant reports and statements; Dr. A gave oral evidence, and was cross-examined reasonably extensively by the father. All parties made submissions, including the father and mother. The hearing was conducted in public; a reporting restriction order was made yesterday (10 March).

Brief background: Care Proceedings

7. S is one of four children of the mother and father. She has an older sister and a baby brother. While S and G (the middle siblings) have profound disabilities and needs, the older and younger siblings do not. The father has lived in England since 1991, the mother since 2005; they lived in the Durham area from 2013. In May 2014, the mother returned to India, ostensibly for three weeks for a wedding, leaving the children in the father's care. The mother did not in fact return until August 2015 and while in India gave birth to her fourth child (October 2014). In May 2015, S was admitted to hospital from home suffering prolonged *status epilepticus*; she was an in-patient until November 2015.

8. In August 2015, the Local Authority issued care proceedings, and the mother returned to the UK. In late November 2015 the parents attended a Case Management Hearing in the care proceedings; I am informed that HHJ Simon Wood advised the parents of the importance of engaging fully with the court process in the interests of the children. On 8 December 2015 they both returned to India where they have been ever since.

9. The final hearing of the care proceedings was listed for 10 days in late-January 2016. Although the parents were not at court, no application was made on their behalf to adjourn the hearing; the Local Authority's application proceeded by way of oral submissions. Counsel for the parents highlighted evidential weaknesses in the Local Authority's case, but the parents' challenge to the factual basis of the *Part IV* care

application, and to the plan of the authority, was perforce circumscribed by their absence from the hearing and the lack of immediate instructions. At the conclusion of the hearing HHJ Simon Wood delivered a judgment (reported as *Re S* [2016] EWFC B7) and made care orders. In doing so, he said this (see §47):

> "The conduct of both parents in this litigation, especially given the repeated warnings that have been given by the court of the effect of failure to participate, has to translate into an inability to prioritise these children. Sadly, since they left, there has been no contact really, asking about the children's welfare. The children appear to be settled and, within their limitations, thriving and making an attachment to their carers now in their placement. It is not suggested that either parent does not love their children. The father clearly loves them very much indeed and there are signs of some kind of bond. But what is completely unfathomable is what it is that drives his views and prevents him from engaging in a way that would better meet their needs."

10. Recognising, of course, the limitations of a forensic process in which the parents, although represented, had not fully participated HHJ Simon Wood, having analysed the evidence, made a number of factual findings, which included the following:

    i) The father holds strong and dogmatic views on the treatment of his children. Some of these views are paranoid and delusional. His insistence on the validity of these views impinges on the ability of the treating team to treat the children effectively. The father is unable to exercise consistently rational judgement in relation to what care and treatments are in the children's best interests, thus placing them at risk of significant harm;

    ii) The father is unwilling or unable to provide relevant information about seizures suffered by both children;

    iii) The father is either unwilling or unable to follow clear medical advice about the administration of medicines and seeks to influence medical decisions on the administration of appropriate medication, either by constant challenge, threat or manipulation;

    iv) The father has made unsubstantiated claims of expertise in science, microbiology, biology, immunology, and pharmacology;

    v) The mother spent 15 months in India without sufficient reason; her lack of contact with her children in that period, by choice, has impacted negatively on their attachment to her and vice versa;

    vi) The mother has failed to exhibit any consistent judgement independent of the father, and cannot be relied upon to protect the children from the father's pursuit of unsuitable medical treatment, drug administration, or diet.

11. There has been no appeal against the orders made.

12. The father's evidence (or more accurately his questioning of Dr. A and his oral submissions) during this hearing over two days has been entirely consistent with (indeed reinforces) Judge Wood's findings at (i), (iii) and (iv) above, and in endorsing her husband's approach, the mother confirmed the validity of (vi) (above).

S's disability and health care needs

13. A joint report prepared by the treating clinicians for S (namely Dr. A, Dr. B, and Dr. C), dated 5 February 2016, provides a detailed and incisive description of S's condition, her functioning, her quality of life, her health risks, and treatment options; it explains fully the proposed limitations to S's future medical treatment under the declaration sought. Dr. Horridge, the jointly instructed expert whose evidence I discuss further below, described Drs. A and B as having considerable knowledge and expertise in the care of profoundly disabled children; she expressed "every confidence that they will know how to manage [S]'s symptoms effectively". Dr. Horridge described the report laid before the court as "exemplary in quality and detail, evidencing a compassionate and thorough approach to decision-making, in S's best interests". I associate myself entirely with Dr. Horridge's comments.

14. The clinicians describe S's condition thus:

    i) Early-onset epileptic encephalopathy with seizures which can be life-threatening and may require emergency care; she has profound cognitive impairment resulting in a profound learning disability;

    ii) A severe visual impairment as a result of disturbance of the function of the brain cortex, leading to difficulties with interpreting visual information;

    iii) Severe motor impairments due to a combination of spasticity and dystonia; she has no independent means of mobilising and is unable to sit, stand or walk independently; she requires assistance to change position, to reach out and touch or hold objects in her environment;

    iv) Severe musculoskeletal complications secondary to her severe motor impairment; these complications have been exacerbated by sub-optimal management of her muscle tone, dystonia and posture in the past; she has a severe scoliosis; her spine is severely twisted to the extent that her rib cage is rubbing on her hip bone; however, severe spinal curvature is now compromising breathing due to restrictions it places on her lung capacity, combined with relatively weak respiratory muscles. She is at a high risk of respiratory failure due to mechanical restrictions on her breathing and frequent respiratory tract infections from which she will find it increasingly hard to recover;

    v) She has thin, brittle, osteopaenic bones; these put her at high risk of bone fractures even with minimal force;

    vi) She has impairment of bulbar function, which means that she has poor gag reflexes and swallowing functions, putting her at risk of choking, excessive secretions, and risk of aspiration; oral feeding is not safe.

vii) She is doubly incontinent.

15. At the hearing before Mostyn J on 4 February, Dr. C's evidence was to the effect (per counsel's agreed note):

i) "[S] is profoundly compromised. She is not unstable at the moment but could collapse at any time.… She is likely to die in the next few weeks or months. She is at risk of collapse";

ii) S is "unlikely to survive emergency treatment";

iii) S is "critically frail and is going to die whatever we do. … Aggressive intervention is traumatic, painful, distressing, intrinsically invasive and damaging".

16. It is clear that S's current level of daily care needs are extremely high; increasing fragility and poor health has made sustaining her life in the community extremely difficult. She shows minimal awareness of the presence of her brother. Her life expectancy has always been significantly shortened, due to the profound nature of her disability and health needs; death in childhood is a not infrequent occurrence in such profound neuro-disability, however recognising what may be the final illness of a profoundly disabled child is very difficult. Dr. A (speaking for the treating clinicians) expresses the view that it is, sadly, possible in S's case to track a general decline in her health and functioning over recent weeks and months and some of this stems back to a relative neglect of her care needs whilst in the care of her parents. If S suffers a cardiac arrest, this will be the consequence of "acute-on-chronic" respiratory failure, with associated severe hypoxia and metabolic disturbance: achieving resuscitation in this situation is extremely difficult, and even if a cardiac output is regained, there is highly likely to be a period of multi-organ failure. Dr. A goes on:

> "[T]he likelihood of successful resuscitation for any child suffering a cardiac arrest, even with access to advanced life-support procedures is fairly low. In S's case this is likely to be even lower, and the medical consensus is that the chances of successful resuscitation, following a cardiopulmonary arrest are virtually nil for S. In addition to the negligible chance of success in the situation of a cardiopulmonary resuscitation, S would be at high risk of sustaining serious physical injury from the process of chest compression, like rib fractures, due to her thin bones and possibly severe bruising. Even if S recovers from the current illness, she is likely to succumb to increasingly frequent respiratory infections in the future, each of which will be life-threatening, and with an increasing risk of being infected with multi-antibiotic resistant organisms."

17. Dr. A and her colleagues describe the benefit to patients who are able to receive treatment in a paediatric intensive care unit; generally, such a unit is able to provide life-sustaining support to a child who has the potential to recover from their underlying illness or injury. S, in her opinion, is not such a child. The clinicians are of the view that it would be technically extremely difficult to provide S with adequate

sedation and analgesia to achieve effective intensive care, including intubation and ventilation. The clinicians are of the combined opinion that there is a very high risk that S would not be able to recover sufficiently from an intensive care episode in order to be able to survive independently once such support was withdrawn. They state that:

> "[S]he would therefore become stuck, and technologically dependent. This is due to the serious and severe nature of her underlying respiratory dysfunction combined with her poor neuromuscular condition, which would make weaning her off the ventilator support very difficult."

They add:

> "If S became stuck on a ventilator in intensive care, unable to wean off the ventilator support, there would be a high risk that she would succumb to a complication, or that treatment would ultimately have to be withdrawn due to futility. Therefore there would be a high risk of S dying a potentially uncomfortable death in an intensive care unit, without the privacy and comfort of familiar surroundings."

It is in these circumstances that the clinicians seek limitations to future medical treatment in S's best interests.

18. The Guardian describes S in her first report (11.2.16) thus:

> "S's quality of life has been described as poor by her present foster carer and staff within her school. It is reported that she is regularly in pain due to her scoliosis of the spine. All professionals accept that S gains little comfort from being in a sitting position, she has recently struggled to breathe whilst in school and on two occasions an ambulance has had to be called. She appears to have been in pain more recently. School staff describe S as regularly stretching out her hand, but feel that this is a reactive movement rather than an attempt to have contact. Sometimes when S is thought to be smiling it can be a muscle spasm following a seizure."

19. In her more recent report (22.2.16), the Guardian has prepared a useful balance sheet setting out the benefits and burdens of treatment, highlighting under 'benefit' the possibility and potential of a prolonged life, and some quality of life, while under 'burden' she identifies the risk of further damage to her by cardio-pulmonary resuscitation, the likely deterioration in her quality of life, further discomfort and distress. Having considered carefully the factors on each side of the balance, the Guardian supports the recommendation of the Trust.

The relief sought by the Trust and the exercise of clinical discretion in practice

20. The clinicians seek the court’s permission to treat S in accordance with their clinical discretion, including whether or not to resuscitate her in the event of a collapse. The specific declarations sought are:

> “(1) Notwithstanding the lack of consent of the father and mother, it is lawful and in the best interests of the child (born 25 July 2008) that the Applicant (Trust) and/or the responsible medical practitioners having responsibility for her treatment and care shall be at liberty to treat her in accordance with their clinical discretion, including any decisions they make whether or not to resuscitate her in the event of her suffering a collapse.
>
> (2) The Applicant’s staff shall generally provide such treatment and nursing care as may be appropriate to ensure that S suffers the least pain and distress and retains the greatest dignity.”

21. In interpreting and applying their discretion, Dr. A told me that the clinicians would be likely to:

    i) Apply a “Do Not Attempt Cardiopulmonary Resuscitation” order/instruction; that is to say that in the event of a cardiopulmonary arrest, S would not receive cardiac compression, defibrillation or resuscitation drugs; it is believed that these would be medically futile and potentially harmful for S;

    ii) Withhold mouth-to-mouth or bag and mask resuscitation, as this would be medically futile;

    iii) Withhold endotracheal intubation and ventilator support in intensive care;

    iv) Withhold non-invasive ventilatory support for S, which it is believed would cause intolerable physical burdens for her and introduce new risks to her health;

    v) Seek to alleviate her suffering and distress with the appropriate use of analgesia such as morphine, and sedatives, in accordance with the principles of good palliative care in the event that S becomes severely distressed or has severe pain as a result of further deterioration in her condition.

    The clinicians are satisfied that this programme accords with the ethical framework published by the Royal College of Paediatrics and Child Health, entitled “Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice” (May 2015) (“the RCPCH 2015 Framework”). The clinicians are keen to emphasise that the limitations set out above are not due to any value judgement about S’s disability, but are due to concerns about her quality of life. They remain concerned that potentially unethical administration of medically futile treatments should be avoided.

The RCPCH 2015 Framework

22. The RCPCH 2015 Framework is self-evidently an essential basis of practice for the medical profession in dealing with clinical decision-making to limit treatment. It also provides valuable direction for a court when it is required to grapple with the ethical and medical issues in a case such as this. The revised Framework was referred to by Sir James Munby P in *Re Jake* [2015] EWHC 442 at [34]/[35], and by MacDonald J in *Kings College Hospital NHS Foundation Trust v MH* [2015] EWHC 1920 (Fam) (see [38]-[42]), and has been relied upon by the Trust and the Children's Guardian in this case to demonstrate that the Trust's approach is both conventional and principled. This is neither the time nor the place to rehearse lengthy citations of the text of the Framework, but I wish to make it clear that I have had specific regard to the following aspects of its guidance, which it seems to me have particular relevance to S:

i) That the relevant factors in assessing quality of life for children with disability in relation to decisions about life sustaining treatment (LST) do not differ from those applied to those without disability; decisions to limit LST in children with disabilities should be made on the same basis as in non-disabled children. [2.4.6.];

ii) There is no significant ethical difference between withholding, limiting or withdrawing (stopping) treatments, given the same ethical objective [2.4.8];

iii) The professional duty to preserve life is not an absolute one that applies at all costs. Treatments should only be provided where they are in the child's best interests [2.4.8];

iv) It is ethical to withhold (or withdraw) life sustaining treatment where such treatment would be medically inappropriate and could not achieve its intended purpose of preserving life or restoring health; or where treatment would no longer be in the best interests of the child in that its burdens outweigh the benefits [2.4.8];

v) A redirection of management from LST to palliation represents a change in aims and objectives of treatment and does not constitute a withdrawal of care [2.4.8];

vi) It is ethically appropriate to withhold or withdraw LST (subject to the above conditions) and to provide appropriate palliative treatments (including analgesia and sedation), even if it is reasonably foreseeable that the latter may hasten death. These steps are a desirable and acceptable part of contemporary end-of-life care and do not constitute euthanasia. [2.4.8];

vii) Limitation of treatment may be justified in the child's best interests where there is no overall qualitative benefit, though "considering quality rather than quantity of life is more problematic because of potential or actual differences in views of the healthcare team and children and families as to what constitutes quality of life and the values that should be applied to define it"; thus if a child's life can only be sustained at the cost of significant pain and distress it may not be in their best interests to receive such treatments, for example, use of invasive ventilation in severe irreversible neuromuscular disease. [3.1.3];

viii) An attempt to provide cardiopulmonary resuscitation is inappropriate where even if successful it is likely to produce more burdens than benefits [3.2.3];

ix) There is a strong moral duty to provide palliative care to children with life-limiting illness [3.2.6];

x) While seeking a second opinion is not a legal requirement in a situation such as this, it does conform to the principles of good ethical decision-making and the due process that good clinical governance requires [3.3.2].

The expert view of Dr. Horridge, Consultant Paediatrician (paediatric disability)

23. Dr. Karen Horridge is a consultant paediatrician with a career long interest in paediatric disability and palliative care. She is Chair of the British Academy of Childhood Disability. She has had access to the papers filed in this application, to the extensive medical records concerning S, has spoken with the treating clinicians, and has had the benefit of meeting with and assessing S. Put shortly, Dr. Horridge concurs fully with the views of the clinicians, both in describing S's condition, and in evaluating the treatment options for her. She supports this application. I therefore select from her report for this judgment only particular features which have assisted me in understanding S's condition, and guiding me in determining this application.

24. Dr. Horridge describes S's marked abnormality of muscle tone known as dystonia, most obviously demonstrated by her kyphoscoliosis or curvature of the spine. As the curvature has progressed over time it has compressed S's internal organs including her lungs, which makes her more vulnerable to chest infections and skin infections. S's spinal curvature is now so severe that this poses the most major risk to her health. The window for correcting this condition has, regrettably, now passed; the clear view is that S would not tolerate intensive care treatment. Dr. Horridge goes on:

> "If she were to be so very unwell that her heart stopped, then in my professional opinion, **it would be unethical to expect anyone to attempt Cardiopulmonary Resuscitation**, because this would be highly unlikely to be successful in saving her life and would definitely be likely to lead to complications, including potential fractures because of her thin bones and would mean that she would be denied a dignified and peaceful death." (Emphasis by bold in the original).

She adds:

> "The risks of intensive care for S in terms of leading to more pain and suffering outweigh any potential benefits. If she is sick enough to be in respiratory failure, it is highly unlikely that even with intensive care, her life will be significantly prolonged. To put S through intensive care would likely change the mode and place of her death and again may deny her the chance to die naturally with dignity. Should S deteriorate and go into respiratory failure, her

> symptoms should be managed at all times to ensure her comfort and dignity."

25. Dr. Horridge explains that the risk of respiratory arrest is greater for S than cardiac arrest; severe kyphoscoliosis affecting body posture is restricting the movement of her chest wall, which in turn restricts her ability to move air effectively in and out of her lungs. There is increasing risk over time that S's lungs are more squashed and that movement in and out of the air sacs in her lungs will reduce over time, reducing her capacity to oxygenate her blood. She also has a degree of upper airway obstruction, caused by dysfunction of coordination of the nerves and muscles around the upper airway. Any future severe infection creates a significant risk of respiratory failure; there is a risk that S would become tired and stop breathing altogether. It is Dr. Horridge's view (referred to at §1 above) that S remains at significant risk of sudden and unexpected death; it is quite possible that she could die in her sleep at night without warning.

26. Dr. Horridge is of the view that S is currently "beautifully cared for" by foster carers. She has an "exceptionally robust care package in place and is extremely well loved and cared for in all respects, with consistency of medication administration, personal care, meticulous attention to her postural management and skin protection."

27. Given that S and G, siblings separated by three years, present with many of the same disabilities, Dr. Horridge recommends the instruction of a geneticist to advise on their specific condition, and to contribute to decision-making about appropriate interventions. This is not a course which the Local Authority or the Trust wish to embark upon at this stage, given the disadvantage of testing without samples from the parents. Dr. Horridge further recommends that the clinical team may wish to seek expert opinion from a senior paediatric intensive care specialist regarding the potential risks and benefits to S of intensive care. Dr. A confirmed that the team had already made communications with colleagues with relevant expertise in other specialist units.

The Parties' positions

28. The Trust argues that the proposed declarations (which I have set out at §20 above) are both necessary and proportionate; they assert that such declarations are entirely in accordance with S's best interests. It contends that I can be satisfied that evidence gathered in the case is comprehensive and balanced; it argues that this evidence is compelling. Specifically, it asks me to accept the evidence of Dr. A, supported as she is by the second opinion of Dr. Horridge.

29. The Local Authority and the Children's Guardian on behalf of S support the grant of the declarations sought by the Trust.

30. At the time of S's sudden deterioration and thereafter, considerable efforts were made by the social workers (and latterly by the Trust) to engage with the parents with the issues involved. It is unnecessary for me to catalogue here the attempts at telephone communication, telephone conversations, and the exchanges of e-mails. I summarise the themes contained in the parents' responses (such as they were prior to the hearing):

i) That S was well when they were caring for her, and that her deterioration is the responsibility of the Local Authority and/or the health professionals at Durham Hospital;

ii) That S and her brother should be sent to India forthwith where the parents can care for her;

iii) That they do not accept that S is or was in a life-threatening state, and would not entertain discussion about end of life preparations;

iv) That they wished the Local Authority to commission second opinions and treatment from internationally renowned specialist experts;

v) That they wish the medical professionals to provide proper / better health care for S (and G);

vi) That S is capable of making a full recovery if the professionals here follow his request;

vii) That they do not trust Dr. B.

The parents confirmed (when I read this list back to them on the first day of the hearing) that I had accurately distilled the essential messages from their communications with the professionals over recent weeks.

31. A telephone conference call was set up on 10 February to provide the parents with the chance to speak with Dr. B. In this discussion (of which I have a note) Dr. B was able to update the parents with a description of S's current state of health. The father claimed (consistent with his comments elsewhere) that the deterioration in S's health was entirely attributable to the care she has received since her removal from the care of her parents.

32. At this hearing, the parents did not give evidence as such, but made submissions repeating many of the themes outlined in §30 above; *additional* themes emerged during this process:

i) That the hospital clinicians have been "negligent" in the care of S;

ii) The views of Dr. Horridge and the Children's Guardian can be discounted as they are based on misinformation from the treating clinicians; in the alternative, Dr. Horridge and the Children's Guardian are under the influence of the treating clinicians, and are not therefore truly independent;

iii) A final decision should be postponed for six months in order for the parents to instruct an Indian expert, and for them to attend in person in court;

iv) By this application it is clear that the treating clinicians wish to "murder" their daughter;

v) Dr. A has not behaved ethically; she has lied; she has spent inadequate time with S in order to form a reliable view; she is guilty of "malpractice", should be removed from the case and disciplined.

33. I mention for completeness, that the family are Hindu; neither the mother nor the father have raised in any of their communications with professionals, or in their submissions to the court, any objection to the relief sought based on their faith, or other spiritual considerations relevant to preparation for the end of life.

The law

34. It was apparent to the clinicians on 3 February 2016 that there was no, or no likely, consensus between them and the parents about what would be best, in treatment terms, for S; hence this application. Having placed the issue in the hands of the Court, it is now the role and duty of the Court to exercise its own independent and objective judgment on the issue. The issue is to be decided by reference to what is in S's best interests.

35. The approach of the court in a case such as this was helpfully distilled into ten key principles by Holman J at [16] in *An NHS Trust v. MB* [2006] EWHC 507 (Fam); this analysis incorporates the important dicta by Lord Donaldson in *Re J (A minor) (Wardship: medical treatment)* [1991] Fam 33 at page 46 describing the very strong presumption in favour of a course of action which will prolong life. Holman J re-stated his ten-point principles recently in *Central Manchester University Hospitals NHS Foundation Trust v A (Withdrawal of Treatment)* [2015] EWHC 2828 (Fam) at [5]; his approach which was specifically approved by Sir James Munby P in *Re Jake* [2015] (above) at [33]. Holman J's list drew upon and explicitly incorporated the 'intellectual milestones' which had been referred to in the Court of Appeal's (then only recently handed-down) decision in *Wyatt v Portsmouth NHS Trust* [2005] EWCA Civ 1181, [2006] 1 FLR 554 at [87].

36. It is unnecessary for me to incorporate the relevant citation from *A NHS Trust v MB* [2006] into the body of this judgment; however as the parents are unrepresented, with no immediate access to English lawyers in India, but with good understanding of the English language, I consider it appropriate to set out Holman J's principles, which I have followed, in an Annex to this judgment.

37. In summary, I am obliged to have regard in this case to the best interests of S, as that phrase is understood in its widest sense, endeavouring to include in the decision I am required to make every kind of consideration capable of impacting upon it. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations. In *Aintree University Hospitals NHS Trust v James* [2013] UKSC 67, [2013] COPLR 492, a case concerning the analogous situation of an adult without capacity, Baroness Hale expressed herself thus at [39]:

> "… 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 to the treatment is or would be likely to be;

> and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be".

38. Insofar as any further gloss is needed on the jurisprudence, it would be to incorporate explicitly the complementary guidance now offered by the RCPCH 2015 Framework.

Discussion and Conclusion

39. The decision whether to withhold or limit life-sustaining treatment in any child with life-limiting illness is one of the most contentious, difficult and emotive decisions which is ever taken by a court. At the heart of any decision has to be a judge's evaluation of what is in the best interests of the subject child, in this case, S. Of the wider principles which a judge considers in reaching his/her decision, considerable weight will be attached to the presumption (though I don't use the term in the legal sense, and it is by no means an absolute right) in favour of the preservation of a child's life; the respect which a judge affords to the sanctity and preciousness of life is not however absolute, and no judge will require treating clinicians to provide treatment to a child where it is futile or where it would not be in the child's best interests. The child in these circumstances has further rights both at common law and under the *ECHR* to be protected against inhuman or degrading treatment, and to respect for his/her private and family life.

40. While the legal and ethical principles engaged here and discussed above are of general application in all cases of this kind, the decision I make is entirely personal to the needs and circumstances of S, taking account of her disabilities (summarised at §14 above) and her perceptions. It is S, and her situation alone, on whom I focus. I am satisfied that the combination of her disabilities render her particularly vulnerable to respiratory failure, while her thin brittle bones, and advanced kyphoscoliosis, are likely severely to impede cardiopulmonary resuscitation in any effective, safe, and/or beneficial way. S is not a child for whom intensive care would bring obvious benefits, as it does for so many children and adults; on the contrary, at best it would be likely to bring her only temporary dependence on artificial ventilation, medical complication, and discomfort. Any life beyond such intensive care would, I find, be of significantly diminished quality, even from its current "poor" baseline (see §18 above), and it would, I find, be adversely affected by regular (I suspect increasing) pain. None of that is intended to suggest that I regard the quality of the care which she is currently receiving as anything but the highest available, as Dr. Horridge has confirmed.

41. Notwithstanding the considerable difficulties in achieving resuscitation for S, I must consider what the benefits for her would be; they are, or would be, in S's case more theoretical than real. She could potentially have a prolonged life, in the care of her current foster carers, and with her brother; that said, it is difficult to ascertain her 'likes or dislikes' or any sense she has of proximity to her brother (see §16 above) so the quality of her life is currently difficult to measure. Even assuming, as I do, that there is or may be some benefit to her by prolongation of life, any perceived benefit is in my judgment significantly outweighed by the considerably compromised situation in which she will be left. Ultimately, failed resuscitation would be likely to strip her of any vestigial dignity as she survives (however briefly) intensive care before inevitably and shortly passing away. It is my view that carefully planned palliative

care would be considerably more beneficial for her than intensive care: transfer into palliation is entirely in accordance with the “moral duty” on clinicians described in the RCPCH 2015 Framework (see §22(ix) above). The treating clinicians have set out how they would propose to interpret and apply the discretion which they seek from the court in the way they propose to treat S; I have summarised this at §21 above. Their approach seems to me to achieve an appropriate blend of humanity and sound clinical practice.

42. I have paid close attention to the wider views of the parents in this case, which I have summarised at §30 and §32 above. They love S and have a unique relationship with her, which in my decision-making has to be (and is) properly respected. I am satisfied that they have had the fullest opportunity to contribute to my determination, having been offered the funding of their airfares to attend the hearing; in the end they participated throughout by telephone.

43. No one can doubt their stress, and distress, at having to confront these extraordinary and profound decisions concerning their daughter; their frustration and sense of impotence in trying to deal with this litigation remotely, even if that is to an extent a situation of their own making, was also palpable. They expressed their opinions about S’s care forcefully, and with more than a little anger during the hearing. As I observed at §12 above, I was able to see for myself what HH Judge Simon Wood had described as the father’s strong and dogmatic views on the treatment of his children. The father’s strongly worded attacks on the individual medical professionals (on Dr. A in particular) and on the health service in general were, however, unwarranted and ill-judged; they suggested a degree of paranoia. As I make clear elsewhere in this judgment, I consider that Drs A, B and C have been, and are, dealing with S’s complex care with exceptional skill and obvious humanity. I reject the parents’ contention that S’s deterioration has in material respects been caused or aggravated by sub-optimal care by the Local Authority and/or her treating doctors; while I acknowledge that there is a coincidence in timing with the recent significant life-threatening deterioration in her condition following shortly from the making of a full care order, it is no more or less than that – a coincidence. Indeed, there is a strong suggestion in the medical evidence that had S received surgery to address the curvature of the spine in the period while she was in her parents’ care *prior* to May 2015, the difficulties of treating her now would not be so acute (see §24 above).

44. The parents have asked for 6 months to arrange to come to England, and to garner further evidence from an Indian doctor; S does not have time on her side. She is critically frail (as Dr. C has observed) and could collapse at any time. The decision has to be made now.

45. I have the considerable advantage in making my decision of well-researched, clearly informed, medical opinion. As I indicated above, I share Dr. Horridge’s view of the exceptionally high quality of care which S is currently receiving from Drs. A, B and C. The clearly expressed and clinically sound views of the treating team are amply re-inforced by the independent views of Dr. Horridge and the Children’s Guardian, and consistent with the RCPCH 2015 Framework. I confirm that I regard both Dr. Horridge and the Guardian as providing views which are truly independent of the treating clinicians and of each other. The Guardian brings to the case valuable knowledge and experience of S (and of her parents) over a period of time, and I am

satisfied that she has approached the assessment of the particular issue here, and in her initiative to seek a second opinion, with fresh eyes.

46. Having weighed these opinions and views carefully, and for the reasons fully set out above, I am satisfied that it in the best interests of S that I should grant the declarations sought, and set out in §20 above, and I do so.

47. That is my judgment.

Annex

An NHS Trust v. MB [2006] EWHC 507 (Fam) @ [16]

"(i) As a dispute has arisen between the treating doctors and the parents, and one, and now both, parties have asked the court to make a decision, it is the role and duty of the court to do so and to exercise its own independent and objective judgment.

(ii) The right and power of the court to do so only arises because the patient, in this case because he is a child, lacks the capacity to make a decision for himself.

(iii) I am not deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.

(iv) The matter must be decided by the application of an objective approach or test.

(v) That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.

(vi) It is impossible to weigh such considerations mathematically, but the court must do the best it can to balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies.

(vii) Considerable weight (Lord Donaldson of Lymington MR referred to 'a very strong presumption') must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive; and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.

(viii) These considerations remain well expressed in the words as relatively long ago now as 1991 of Lord Donaldson of Lymington in *Re J (A minor) (Wardship: medical treatment)* [1991] Fam 33 at page 46 where he said:

> 'There is without doubt a very strong presumption in favour of a course of action which will prolong life, but … it is not irrebuttable … Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment… We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life …. Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it

> increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.'

(ix) All these cases are very fact specific, i.e. they depend entirely on the facts of the individual case.

(x) 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."