Neutral Citation Number: [2022] EWHC 938 (Fam)

Case No: FD21P00954

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 20th April 2022

Before :

MRS JUSTICE ARBUTHNOT

- -

Between :

BARTS HEALTH NHS TRUST
HOMERTON UNIVERSITY HOSPITAL TRUST

Applicants

-and-

HM

1st Respondent

-and-

SM

2nd Respondent

-and-

LONDON BOROUGH OF HACKNEY

3rd Respondent

- -
- -

Conrad Hallin (instructed by **Hill Dickinson**) for the **Applicant**
Christopher Osborne (**Cafcass Legal**) for the **1st Respondent**
Judith Mayhew (instructed by **Cale Solicitors**) for the **2nd Respondent**
Abimbola Badejo (instructed by **London Borough of Hackney**) for the **3rd Respondent**

Hearing date: 13th April 2022
Draft Judgment: 14th April 2022

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JUDGMENT

Mrs Justice Arbuthnot:

Introduction

1. I am concerned with HM who was born on 3rd March 2006 and is aged 16. She is the third child in a family of six children who live with the second Respondent SM, their mother who is supported by her partner.

2. HM was born with a number of challenging medical issues. She has a genetic chromosome abnormality called 1p36 deletion; epilepsy; severe global developmental delay; kyphoscoliosis; risk of aspiration and severe faltering growth which shows itself in a minimal weight gain in the past few years and in particular weight loss in the past 12 months and feeding difficulties.

3. Although HM is non-verbal and uses a wheelchair she is able to express herself through making sounds and through smiling, laughing, crying and making hand gestures. The description of the guardian is that HM sits at the heart of a lovely large family. The guardian visited her not so long ago and witnessed her closeness to other family members and her obvious happiness when her siblings returned from school.

4. Initially it was thought that HM would not survive beyond her first birthday and it is thanks to her mother, SM's great care for her daughter that she has just passed her 16th birthday. This must have been challenging at the best of times, with the number of complex medical issues that HM has to cope with but even more so when HM has five siblings aged from 18 to three.

5. I heard evidence from the mother today and heard this remarkable woman articulate her deeply felt concerns about the risks the Trusts' proposals might

pose to HM. Her deep understanding of HM means I have to listen with particular care to what she says is in her daughter's best interests.

6. There have been some rocky moments in the relationship between the mother and some of the clinicians (and others) working from the Trusts but the parties very sensibly decided that it would not be helpful or constructive to dwell on the past.

7. I was particularly grateful to have the assistance of very able and experienced counsel who explored the clinicians' and the mother's evidence skilfully and sensitively and made cogent, fair and balanced submissions at the end of the case which I found extremely helpful.

8. For convenience I have referred to the Trusts as "the applicants" and to the second respondent as "the mother".

Application

9. Barts Health NHS Trust and Homerton University Hospital NHS Trust ("the Applicants") apply for declarations that HM lacks capacity to make the material decisions to rebut the presumption of capacity and that it is lawful and in HM's best interests for a particular care plan of treatment to be followed.

10. The second declaration the Applicants seek to be made under the inherent jurisdiction is that it is lawful for HM to be admitted for a period of up to seven days for observation before having a nasogastric ("NG") tube inserted to enable HM to receive supplemental feeding; until she has gained optimum weight for her to tolerate a general anaesthetic which would allow for a percutaneous

endoscopy gastrostomy (“PEG”) tube to be inserted by which she could receive supplemental feeding including at night.

Issue

11. There are two issues for me, first, whether HM lacks capacity. This is not challenged. HM is non-verbal and has “Profound and Multiple Learning Difficulties” (“PMLD”). She does not have the capacity to make the material decisions. The presumption of capacity is rebutted, and I make the first declaration.

12. The more difficult issue is whether the care plan as amended is in HM’s best interests. As a precursor to the decision, the mother disputes that her daughter is ‘malnourished'. Even if she is, the mother says the risks outweigh the benefits of the procedures whilst the applicants supported by the guardian take the opposite view. They argue that HM is malnourished according to the medical definition and that the benefits of their care plan outweigh the risks. The court must balance both sides of the equation to reach a decision, as part of that balance this mother’s views who knows her daughter very well better than anyone else must be given particular value.

Parties’ positions

13. The applicants’ position is that HM is malnourished. The amended care plan is that HM is to be admitted to hospital, where between days 1 and 7, baseline measurements and bloods will be taken to assess her weight and blood count and protein levels and during this period she will continue with her present community home and school feeding plan.

14. During that first period, her oral intake will be carefully measured as well as her output (urine etc) to assess hydration based on weight. At that stage if her oral intake is not sufficient for adequate growth and weight gain then nasogastric 'NG' tube feeding will take place before HM has gained sufficient weight so that she could tolerate better a general anaesthetic when a PEG will be inserted.

15. HM's mother opposes the application. Her strongly held view is that HM is not malnourished. The risks of the insertion of the tubes required for NG and PEG feeding including the use of a general anaesthetic are too great. All the family are lean and HM is no leaner than her siblings.

16. Mediation was attempted between the clinicians and the mother but it did not work out satisfactorily.

17. The local authority feels it has to support the unanimous view of the clinicians. In his submissions Mr Badejo says the medical evidence all goes in one direction that the risks to HM will get worse if she is not admitted into hospital for these procedures to take place.

18. In February 2022, the guardian proposed for an adjournment for a geneticist to be approached to give their opinion as to whether the particular genetic chromosome abnormality called 1p36 deletion may have caused HM's fluctuating and low weight. The expert was consulted and was not able to assist. Having considered that evidence as well as updating evidence from the clinicians the guardian's final position was to support the application for the declarations.

Law in relation to the court's approach to 'best interests'

19. I cannot better the exposition of the law as set out in the Mr Hallin and Mr Osborne's position statements on behalf of the applicants and the guardian. I set out the law below assisted by their documents.

20. The principle of 'best interests" encompasses medical, emotional and all other welfare issues.

21. The most recent consideration of the principle is to be found in *In Manchester University NHS Foundation Trust v Fixsler & Ors* [2021] EWHC 1426 (Fam) (28 May 2021) where MacDonald J considered previous authorities and provided a helpful summary of the application of the best interests' test:

> *"*57. As I have observed in previous cases, 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:
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> 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.

58. 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."
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> 59. 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."
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> 60. In the case of *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ again reiterated that: "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."

Evidence

22. I was provided with a bundle of evidence from the specialists who have been treating HM over a number of months and years. The statements included those from Dr Y a Consultant Paediatric Gastroenterologist, Dr X, a Consultant

Paediatric Neurologist, Dr Z, a Consultant Paediatrician and Ms W a Dietician at Homerton University NHS Trust. I heard from Dr Z, Dr Y and Dr X for the applicants. The mother then gave evidence as did the guardian.

23. The evidence from the doctors went in one direction only. They said as one that HM is malnourished, her case had been considered by a multi-disciplinary team ("MDT") and the team including five specialist consultants agreed that this was the case. Dr V was a consultant at King's College Hospital from whom a second opinion was obtained She provided the same view as the internal clinicians but said that a seven day to two-week observation before a NG tube was inserted might be helpful.

24. The crucial evidence from the specialists was that HM's weight was dropping lower and lower with occasional fluctuations and was one of the two most significant and potentially fatal risks to HM's health. The second was her epilepsy.

25. The most striking evidence in relation to HM's weight from the Trust was given by Dr Z.

26. Dr Z provided two growth charts produced by the Royal College of Paediatrics and Child Health. The charts were at C152 of the bundle, and her height and weight were plotted showing how HM's growth compares to other girls at any particular age.

27. The charts have centile lines which show how in this case HM is developing compared to other girls of the same age. The centiles go from .4 up to 99.6th centile. Currently HM's weight is below the .4 centile which would mean if you

compared her with 100 girls of the same age, HM would probably have the lowest weight.

28. The chart at C152 is in two parts, the first from the age of two until eight and the second from eight to 16 (HM's current age). Dr Z also provided a table of HM's weight measurements and at C209 brought that up to date.

29. Dr Z's evidence was clear, on the growth charts which plotted HM's weight between the age of 2 years until almost aged 8 and a half , she was growing along between the .4 centile to the second centile. These were measurements taken from medical and school notes and were consistent, (ignoring one outlier measurement).

30. The second chart on C152 showed HM between the age of 8 and a half and 16. Her weight had dropped beneath the .4 centile. The point made by Dr Z is that HM had her complex medical conditions from birth and between the ages of 2 and 8 and a half she still had capacity for growth between .4 and 2nd centile. From the age of eight and a half to 16, she had not been able maintain her growth, it was flattening progressively. It was increasingly below .4 centile and dropping further all the time.

31. Dr Z provided a table showing HM's weight on 4th December 2020 at 25.4kg then at aged 15 years on 5th March 2021, she weighed 26 kgs. By the time of her 16th birthday, she is weighed on 4th March 2022, when she is 21.8kg.

32. HM's weight measurements were brought up to date by Dr Z at C209 where it is said she weighed 23.25 kgs on 11th March 2022 and 1st April 2022 when she weighed 22.90 kgs (C209). I notice she did not appear to be weighed at the

doctor on 8th April 2022. These weights were well below what she weighed on or about her 15th birthday.

33. Dr Z said in evidence that she was sorry to have to say that HM was so malnourished when you saw her in person that she looked "purely skin and bone" and has not much muscle left. Dr Z said she "still has some muscle as she can move but she is so malnourished". She repeated how sorry she was to have to say that.

34. The specialist Dr Y, the Consultant Paediatric Gastroenterologist, provided the Personalised Paediatric Dietetic Care and Treatment at C200 of the bundle. If the Court made the declarations requested by the applicants, days 1 to 7 would be for observation of HM with baseline measurements taken and other procedures. Days 8 to 9, a NG tube would be inserted by nursing staff and supplemental feeding would start. At some time after once HM's weight is increasing a PEG insertion would be considered and thereafter there will be training for the mother and any other carer as well as a homecare company to assist with the feeding in the community once she is discharged at around the 28 day mark.

35. Dr Y gave evidence too about HM's weight. He too described her as malnourished. Whether that was the correct medical description or not, another way of describing her weight was that HM was severely underweight.

36. Dr Y set out the risks to HM of being so severely underweight in his first statement at paragraph 48 page C9 of the bundle. The risks were as follows: HM could deteriorate very quickly into the severe end of malnutrition which

could happen at any point. If she were to get a chest infection, she would not have the energy reserves needed to fight it and again could deteriorate very quickly. This would put her at high risk of death. Malnutrition would increase the risk of pressure sores because of the lack of fat to protect her. Osteoporosis in later life was a higher chance where the bones were not getting the nutrients they need for density. Malnutrition also can cause irritability and other changes in behaviour including low energy levels.

37. Dr Y set out in his evidence the risks to HM of the NG tube and the PEG tube procedures. He said that the benefits to HM outweighed the risks to her in the short term. In relation to the seizures that the mother was particularly concerned about, the doctor confirmed that their Anaesthetic team at Barts Hospital anesthetise a lot of children and young people who have epilepsy and she would be kept in hospital post operatively and would receive immediate treatment if she had a fit.

38. Dr X the Consultant Paediatric Neurologist explained in her statements and evidence that the risk of sudden unexpected death from epilepsy (SUDEP) happens in 1:4500 adolescent children with epilepsy and those with pharmacoresistant epilepsy, nocturnal seizures and learning difficulties are more at risk. She said that HM's risk of SUDEP already exists and the risk would not increase as a result of the proposed treatment. There was no link between having a NG tube or a PEG and an increased risk of SUDEP.

39. Dr X said that she had told SM that they prepare children with epilepsy well for the procedure. Whilst in hospital the child receives their usual medication and

if a seizure were to happen then they would immediately intervene and give medication.

40. In her evidence Dr X explained that the insertion and removal of the NG tube was so rapid that it may not trigger a seizure and that pre-insertion medication should ensure that. If HM did have a seizure her team of specialists would be ready to ensure it was controlled immediately.

41. Dr X said one of the advantages of NG feeding leading to weight gain and the insertion of a PEG tube is that a ketogenic diet could be used which assists with hard to control epilepsy in children. This might reduce seizures but can only take place with children who are not of a suboptimal weight. This would be life- changing for HM.

42. As set out above, Dr Y had approached Dr V at Kings College Hospital for a second opinion “from a gastro point of view” which was set out in a letter dated 9th August 2021. Dr V said the concerns is that HM is “quite underweight and has not been meeting her calorific requirement from oral intake”. Dr V contacted the mother and established HM’s history and her feeding regime.

43. Dr V suggested that HM be admitted for observation of her food intake which would allow recording of her input and output and a calculation of her calorie intake and requirement. She could have her weight monitored during that time.

44. When Dr V suggested that to the mother’s partner, he said they were concerned that the stress of admission might exacerbate her epilepsy. Dr V explained that Royal London would be best for admission as they would have the appropriate team on hand.

45. Dr V's recommendations were agreed with his gastro multidisciplinary team at a meeting on 12th August 2021, Dr V said that it would be in HM's best interests for her to be admitted to Royal London "to observe and optimise oral intake as well as to calculate calorie intake to see if it meets her calorie requirement for adequate growth and weight gain. In their experience with patients with a similar background to HM, these types of admissions can take at least 1-2 weeks. If oral intake is not adequate for calorie requirement for adequate growth and weight gain based on assessment by the paediatric dietician, then enteral tube feeding is indicated" (C39).

46. I was provided with the mother's statements as well as a written complaint she had made against Dr Y and other healthcare professionals. I was pleased to see that none of the counsel thought it was appropriate or helpful to revisit the complaints made by the mother or what the hospital staff have said about the mother. I do not feel that is in HM's best interests for me to revisit what has been a fraught relationship. In my judgment, the clinicians and SM now need to focus on the future.

47. SM set out her views that HM should not be forced to undergo a treatment which puts her at risk and "will unquestionably lead to a deterioration in her overall health" (para 8 page C54).

48. The mother gave evidence in a compelling and very impressive way. A remarkable woman, driven by extraordinarily strong maternal instincts to protect her "ray of sunshine". To say her life bringing up her children must have been difficult was an understatement. When HM was born she had three-year-old twin boys to cope with as well as her new daughter's complex issues.

I am quite sure that many parents would have given up, but it was clear from the way the mother gave her evidence that she has fought for HM for years.

49. I hope the mother will forgive me for saying that her poor relationship with the doctors at the Trusts is the reason which has led her to question whether they have HM's best interests in mind. Poor communication was possibly present. The mother has to realise too that all doctors are desperately busy and sometimes it is not possible to give as much time to a parent as that parent would want.

50. I had no doubt when I listened to the doctors' evidence that although they could not have loved her daughter in the way she did, in their very professional way they wanted the absolute best for HM. When the mother meets with the clinicians in the months and years ahead, I would urge her to give them the benefit of the doubt. She and her partner (and the siblings) are not the only ones who want the best for HM.

51. The mother had had unfortunate experiences with HM of the use of NG tubes in 2019 and these undoubtedly had led her to be concerned about the procedure three years later. The mother pointed out that she had agreed to the insertion of NG tubes in 2019 and to other medical procedures undertaken with HM.

52. HM had been to hospital after seizures in March and April 2019. She had been fitted with a NG tube on both occasions then and the mother said in March 2019 that HM had vomited within a couple of hours of the tube being put in place. Because of the stress she suffered HM had a seizure and became very distressed, and the tube had to be removed.

53. In April 2019 after the NG tube and seizures, HM was placed in an induced coma, on a ventilator. She had to be put in splints to prevent her pulling out her tubes. The mother has splints at home to stop her doing this.

54. In terms of HM's weight, the mother says HM grows at her own pace and apart from a few fluctuations always maintains "her own centile". In court today the mother said that HM was below average weight for a 16 year old but that she was not malnourished.

55. In her evidence, the mother said that HM does not get ill due to weight issues and the absence of hospital admissions due to her nutrition or lack of calories to show that she is not suffering form any form of malnutrition. The mother says that HM is not lethargic, she does not have low mood or a lack of appetite and does not become ill often nor do any wounds take a long time to heal.

56. Other indicators are not present either: she does not have broken hair or fragile or discoloured nails. Her low weight has been "a constant throughout her life". Her siblings are lean too.

57. In her evidence to me this afternoon, the mother describes HM in these vivid terms: she is very active, although she is in a wheelchair, she has very good hair, she is very alert and has "amazing skin". Significant to the mother was the fact that of the six children, HM was the first to be allowed back to school. She had not had Covid nor any vaccinations, but the school did not consider she was at high risk.

58. The mother says that HM's blood results are significant as they show that she is not lacking any minerals vitamins or nutrients. All this indicates that the mother

has established a nutritional feeding plan “to ensure that her calorie intake is optimal”.

59. The mother said that HM whilst had “dips and fluctuations in weight (during menstruation, periods of constipation and during clusters of seizures), she remains on an upward trajectory of growth despite never matching that of an average girl of her age”. She says that HM menstruates regularly and is active and alert. The mother points out that HM’s weight has always been a consistent feature in her life. She explained that HM’s most pressing problem to do with her stomach was her constipation. She told the court today of the many medications she has tried to unblock this problem, all to no avail.

60. In terms of the risks, the mother says that the procedures can and will exacerbate HM’s seizure frequency as well as post procedures “the adverse reactions and common side effects will be particularly detrimental to HM”.

61. In terms of specific risks HM would be able to lift her clothes and dislodge the NG especially if she found it uncomfortable. If she had a seizure at night during PEG feeding this “could have terrible consequences for her”. Dr Y had explained in his evidence that to prevent a child or young person from pulling out a NG tube it is taped to the child’s face and behind the ear and runs down the child’s back’.

62. In summary at her paragraph 103, the mother said she was opposed to the proposal for NG tubes and PEGs for many reasons which included that HM was not and had never been malnourished, she had always been underweight and had no feeding issues, she received the recommended calories daily at home and

at school, her risk of aspiration was being managed and the only time she aspirated was when doctors attempted to feed her using an NG tube in 2019. Furthermore, if the local authority had had any concerns about her ability to feed HM they would not have removed HM from the Child Protection Plan and stepped her down to a Child in Need.

63. The mother exhibited her lengthy complaint dated 4th November 2021 to PALS about Dr Y, Dr Z and Ms W the safeguarding lead for Bart's Health Trust and the Trust's response of 21st December 2021.

64. The mother exhibited a dietetic summary dated 16th September 2021, setting out HM's weight between 7th November 2018 and 16th July 2021. She is usually weighed monthly although I noted there was a period of ten months in the records where no weight was recorded and that between 11th October 2019 and 20th August 2020 she lost just under 4 kg.

65. I heard briefly from HM's guardian. In her first report dated 8th February 2022, she sets out the doctors' and the mother's concerns. She explains that SM "firmly believes" that HM's epilepsy is the condition that is most likely to prove imminently fatal and she does not accept that her weight presents the same threat.

66. The guardian in her first report highlighted her concerns at paragraph 18. She was concerned whether HM had sufficient "emotional and psychological resilience to manage this interim journey" (of having first an NG tube inserted and then a PEG tube). The guardian had spoken to Dr Y who explained that "irrespective of her diagnosis she would be expected to gain weight". The chart

they use allows for underlying conditions. Dr Y told the guardian that the reason for HM's low weight was an insufficient calorie intake or because she was not retaining her calorific intake. Whichever it was "each means that she does not have enough calories to grow".

67. The guardian also spoke to Dr X who explained the gravity of HM's epileptic seizures. Dr X suggested that her genetic condition may be a factor in her failure to gain weight and that Dr P at the Royal London Hospital might be able to help with that.

68. In terms of her wishes and feelings set out at paragraph 22 of her report, the guardian said that HM would want her life to remain stable. She would struggle with an extended stay away from home.

69. The guardian acknowledged, at the same time, that the proposed treatment could improve HM's overall quality of life and that all such procedures carry a degree of risk.

70. Her position in her first report was that when considering HM's welfare she was concerned "about the proposed treatment prompting a domino on the rest of her health including her physical and emotional welfare" (paragraph 24). She questioned whether it might be useful to obtain clarification about whether HM's genetic disorder affects her ability to gain weight. The guardian recommended a short adjournment to obtain that information.

71. Dr P's letter is at C131 of the bundle and is dated 3rd March 2022. Unfortunately, there was no easy answer to the question whether HM's

particular genetic syndrome (1p36 deletion) had any bearing on her slow weight gain. Dr P met the family and Dr X on 28th February 2022.

72. Dr P was told by the mother that the current community dietetic plan is for HM to receive 2500-3000 kcal a day "though HM does not always meet this and that frequent episodes of constipation (managed with oral Movicol) further reduce her oral intake".

73. Dr P summarised the dispute as the Trusts considered a structured re-feeding plan was needed whilst the family felt that HM's health has not been compromised by her low weight and were concerned that any invasive procedures may lead to a worsening of her seizure activity.

74. Dr P said that growth of those with 1p36 disorders is variable and that "there are no specific growth charts available for this condition from research literature". A small number of individuals had had their growth studied and "most have measured in the low-normal range, though a few have continued to track under the 0.4th centile. Dr P encloses a leaflet which mentions that some children mostly under two years of age have benefited from a temporary NG or PEG use.

75. Her conclusion is at C133, "it is not possible to say whether the genetic change itself (1p36 deletion) is a cause of low weight/poor growth, despite sufficient calorific intake. To my knowledge, no specific genes within this deleted region have been associated with growth specifically". She then says "while HM's 1p36 deletion may be contributing to her small stature and suboptimal weight

gain, there are many other factors that influence this, not least ensuring she is consistently receiving sufficient calorific intake for growth".

76. The guardian wrote a second report after receiving Dr P's letter. Dated 7th April 2022, she had spoken to SM on two occasions in March and April 2022 and also to her partner and advocate AB. The guardian had considered Dr P's letter and she concluded that the opinion from the expert did not "exclusively or conclusively attribute HM's genetic condition to have impacted her low weight".

77. The guardian took into account Dr Z's evidence set out above of HM's growth which highlighted the difference in her weight between just after her 15th birthday and just after her sixteenth. The difference was just under 5 kg, the difference between 26 kg in 2021 and 21.8 kg in 2022.

78. The guardian took into account the mother's views of the risks to HM and set out that the Trusts were confident they could manage any potential risks that may arise which they said were straightforward for the majority of children. The guardian said that despite her retaining concerns about how HM would cope emotionally physically and psychologically in the short to medium term with an extended hospital admission, she balanced that against the potential for a decline in health if she did not increase her weight.

79. Her conclusion was that she supported the Trusts' application and she endorsed Dr V of King's College Hospital's approach that she should be admitted to be monitored before a NG tube is put in place.

Discussion

80. I apply the law as it is set out above.

81. The first question is whether HM is malnourished. The doctors are using a medical term when they use the expression malnourished which is defined by the Royal College of Paediatricians and Child Health. SM does not accept her daughter is malnourished, she says she is below average weight which is what she has always been.

82. The most striking evidence on the point is from Dr Z's charts and tables. The concern of the clinicians is that whilst between the ages of two and eight and a half, HM was tracking the .4 centile, from the age of eight and a half to 16 she has gone increasingly downwards and is now at about -7 beneath .4. This conforms with the medical definition of malnutrition.

83. Having said that, I understand and sympathise with the mother's reaction to the use of that word. A more sensitive expression might be 'very underweight' but it is not the strict medical definition used by the clinicians in this case.

84. The point is, as is accepted by the clinicians involved in HM's care, it is not the mother's fault that her daughter is not taking in enough of the liquidised feed or food supplements to enable her to gain weight. I heard Dr Y in re-examination explain why HM would have not been able to take in enough calories, he said she eats a little and then gets tired and then stops eating. Another witness explained how when she no longer wants to eat she just shuts her mouth with the rebellious streak of the teenager she is. Feeding HM and ensuring she receives the calories she needs is very difficult but the evidence from Dr Z and

Dr Y is impossible to challenge, she is very underweight and in medical terms is malnourished.

85. The next question is whether the declarations sought by the Trusts are in HM's best interests. I consider the matter objectively on the evidence before the court. My focus is on HM and what is best for her. I give particular value to SM's views. She is correct to say that there are risks with this proposed procedure and that in particular when the NG tube and the PEG tube are inserted, the pain caused may bring on a seizure.

86. Dr Y set out the risks of each procedure. In relation to the NG tube, the risks were at insertion or if it was dislodged. The doctor explained that there is a risk of aspiration if the NG tube is not inserted in the right place and the feed goes into the wrong place but the clinicians check it is in the right place before starting feeding.

87. The mother points out that HM is sufficiently dexterous to be able to dislodge the NG tube. The doctor says they are used to children and young people who may do that and can ensure the tube comes around to HM's nose from behind her head. In any event HM will be carefully monitored in hospital and she will not be discharged until the NG tube is working. The other risk is from the irritation as the insertion is taking place causing a seizure but once it is in there should not be an increase in seizures.

88. In relation to the PEG tube, Dr Y said Dr R, the Paediatric Surgeon had explained the risks to SM. The benefit of the PEG tube over the NG tube was that medication can be given straight into the stomach without the risk of the

tube being pulled out or it becoming dislodged. The mother was particularly concerned about HM's constipation and the PEG tube would make the administration of medication much simpler.

89. There was a small risk of infection at the site of the PEG tube but it would be easily treatable. The doctor said the procedure is often given to "neurologically disabled patients who suffer seizures" (C12 paragraph 56.3). The tube is given under local anaesthetic and although there is some pain after a week it is minimal to none. It was suggested that pain killers could be given to ensure that the pain did not trigger a seizure in HM.

90. I was satisfied that Dr Y (in combination with the MDT team including the epilepsy specialist Dr X) had the risks of each procedure well in mind and had a plan of ways to mitigate them.

91. Dr X said that if the declarations were made by this Court her specialised team were ready to react to any seizure. It would take place in a controlled environment in hospital. As Dr X explained too, they would prepare and ensure HM was medicated to an extent which reduced the chances of a seizure being provoked.

92. As Ms Mayhew reminded the Court in her closing submissions, the mother had had to live with the fear that her daughter might die at any time. SUDEP happens to one child in 4500 who has epilepsy and HM has all the characteristics which make that more likely. Again, I turned to Dr X and her team who would be monitoring HM and her epilepsy and ensuring she had the medication to prevent or reduce any epileptic attack.

93. A particular concern set out by the guardian in her first report was significant in my judgment. The Guardian was worried about the emotional and psychological effect on HM of being removed for 28 days from the bosom of her family to a place where she would be surrounded by strangers.

94. The evidence from the clinicians was that HM when admitted could be in a cubicle of her own but the mother who knows her child the best pointed out that her daughter thrives in busy places. Given the choice between a trip in a taxi or a bus, HM would always choose a bus. She likes the "hustle and bustle". She would feel lonely in a cubicle. That might be something that the mother should discuss with the hospital prior to admission.

95. The concerns of the guardian were lessened when she heard from the doctors the efforts of the MDT to ensure that there was wrap around care of HM. The MDT includes play therapists and educationalists as well as speech therapists. All would be involved with her care.

96. The mother suggested that the procedures could be delayed and Ms Mayhew for SM suggested that other NHS Trusts should be approached to see if they might be able to take on the care for HM due to the difficult relationship between the mother and the lead clinicians, in particular Dr Y.

97. Very helpfully at the Court's request, Dr Y approached two trusts during the lunch adjournment in this one-day case. The Trusts approached said that a delay of about 12 weeks at a minimum could be anticipated whilst their MDT decided whether to take up the referral. There is no guarantee that they would. One of

the trusts approached said they were very short of beds and had children being held at other hospitals whilst a bed at theirs became available.

98. When I came to stand back from the evidence, I found I was giving particular weight to the risks to HM from her lack of growth as set out by Dr Y. I considered that the risk of infection was the most serious immediate risk along with bed sores. In the longer term, osteoporosis would be a concerning risk but with Covid rampant, the risk of infection and HM's lack of reserves to fight such infections at her current weight were extremely concerning.

99. The mother said with force that she had not seen any sign of her daughter being underweight. Her skin, nails and hair are all in a very good state. HM is not bad tempered or moody and shows none of the other signs of being seriously underweight. She does not catch infections easily and is hardly every ill. She was allowed back to school before any of her siblings which was a sign that she was not at risk said the mother.

100. On the other hand, I had to accept the medical evidence which was clear that HM is at immediate and serious risk, and at such risk that although these concerns had existed and been voiced since 2016, the clinicians considered that a three month wait to find another trust which would take HM would put her too much at risk of serious illness or death. If she could not fight off an infection an even more serious procedure of inserting a central line close to her heart would have to take place.

101. The doctors were clear, that the longer these procedures were postponed, the more difficult it would become to increase HM’s weight by the use of NG tube before a PEG was inserted.

102. Having considered what is in HM’s best interests, despite the considerable value I place on the mother’s knowledge and understanding of her daughter, I consider the risks of serious infection and other issues will increase as her weight falls further away from the .4 centile. Increased infections can lead to the worsening of seizures. There is an immediate risk now. Dr Z was clear that there may be no outward signs of HM’s vulnerability but this did not mean she was not greatly at risk from her underweight state. These procedures are a risk but they are manageable and these clinicians in my judgment have the experience and the professionalism to manage HM safely.

103. In the short term, and 28 days or so in the coming weeks is a short term, HM may not enjoy hospital and may be worried that she is away from her family. She may suffer for a short time from the insertions of the tubes. I have no doubt though that the hospital including the MDT will wrap her around with the care that she needs, they will ensure she is as happy as she can be in the circumstances. Any emotional harm will be mitigated by the play therapists but more importantly than that HM will have the support of her family who will be able to visit and very soon she will be back home.

104. The specialists in the hospital will control and measure her input and output (as the clinicians put it). In the medium term the recurring difficulty with constipation combined at times with her period, which has caused her much pain and suffering, and increased her seizures may well be something the MDT will

be able to work out to try and get to a balance of medication, fluid and feed to make HM's life more comfortable.

105. There are benefits to the procedures which have been set out by the clinicians which are over and above the benefits of gaining weight. A special ketogenic diet can be provided once a PEG is inserted which can be used to treat hard to control epilepsy in children, that cannot be done until she puts on weight. Another advantage of the PEG tube is that feeding can take place at night which would remove what must be considerable pressure on the mother and the school to ensure she gets enough food during the day. That may well allow HM to have more fun in the day.

Conclusion

106. I can understand the mother's concerns about the risks of seizures. In my judgment, any risk will be mitigated by the specialist teams on hand. There is a lesser risk of SUDEP in hospital. The better resistance to infection and other more long-term benefits are significant and in my judgment they far outweigh the risks to HM of the procedures set out in the amended care plan.

107. I make the declarations as sought by the Trusts and approve the Personalised Paediatric Dietetic Care and Treatment Plan provided by Dr Y at C200 of the bundle. This is in HM's best interests.

108. I have set out above that the mother and clinicians have had a difficult relationship. The mother is fiercely and impressively defensive of HM but she must try to accept that the clinicians with their combined 80 years of experience

(at a rough guess) will have come across children and young people with the very same complex medical issues that HM has.

109. The doctors do want the best for her, of course not quite in the way the mother does, but when they consider HM, their advantage is that they draw on their vast experience of what has happened to other children in similar situations. SM should really try and give the clinicians the space and an appropriate working environment for them to do their job. If she does that, then all of the people caring for HM will be working in her best interests which can only help her get the best from these procedures.

110. That is my judgment.