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

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IN THE FAMILY COURT (Sitting at Middlesbrough)

No. MB22C5073

Neutral citation number: [2023] EWFC 138

The Law Courts
Centre Square
Middlesbrough, TS1 2AE

Friday, 31st March 2023

Before:

HIS HONOUR JUDGE BROWN

(In Private)

BETWEEN:

MIDDLESBROUGH BOROUGH COUNCIL

<u>Applicant</u>

- and -

- (1) M
- (2) F
- (3) THE CHILDREN

(through their Children's Guardian) Respondents

Mr F. FEEHAN KC and Ms K. HART (instructed by Legal Services) appeared on behalf of the Applicant.

Mr N EKANEY KC and Ms L. MCKENZIE (instructed by Cygnet Family Law), appeared on

behalf of the First Respondent

Mr T. DONNELLY and Mr A PIKE (instructed by BBNM Law), appeared on behalf of the Second Respondent

Ms C. WORSLEY KC and Ms K FENWICK (instructed by DMA Law), appeared on behalf of the Children via their Children's Guardian, Claire Stainthorpe.

JUDGMENT

- 1. The court is concerned with the welfare of 3 children, A, B and C.
- 2. The mother of the children is M. The father of B is F2. F3 is the father of A. He has not seen his son for some time and his location is currently unknown. F is C's father.
- 3. Care proceedings in relation to A were issued on 22nd August 2022, with proceedings following in relation to the other 2 children on 9th November 2022.
- 4. Following the issue of proceedings A was placed in the care of the maternal grandfather and his wife, MGPs pursuant to an interim care order. B and C have remained in the care of the M and F.
- 5. A was born with a number of medical conditions and issues:
 - i. A genetic disorder: 22q11.21 microduplication.
 - ii. Gastrointestinal issues.
 - iii. Left uveal coloboma.
 - iv. Hearing loss.
 - v. He has developmental delay and communicates via sign language.
- 6. The catalyst for the proceedings was the increasing level of concern expressed by doctors involved with A that the ongoing problems that he had with his feeding and digestion, represented a perplexing presentation, with the history of A's problems as provided by his mother not marrying up with the clinical picture as understood and witnessed by the treating doctors.
- 7. This gave rise to a belief that although A clearly had some challenging medical conditions, the management of his feeding and digestion had been greatly influenced by the mother's actions

in terms of what she reported and how she conducted herself. The conclusion was reached that the mother was fabricating and exaggerating symptoms of illness in A, with the consequence that over many months and indeed years he had been subjected to unnecessary medical interventions, operations and regimes of feeding. This conduct had caused him and made it likely that he would suffer significant harm.

- 8. It was alleged that F who lived with the mother throughout this time failed to act to protect A by calling out the mother's irrational and harmful behaviour or by providing a rational counterpoint to the mother's approach to A's care and treatment. As the hearing progressed, the Local Authority indicated that it did not believe that the evidence supported a finding of failure to protect against F and did not pursue this in the context of the fact finding hearing. That said his role within the household at this time was not irrelevant and may be the subject of closer scrutiny in the context of the welfare hearing should findings of fact be made in relation to the mother's overall conduct in relation to A.
- 9. The mother accepts she may have been excessively anxious and has at the conclusion of the evidence accepted that she had exaggerated symptoms due to this anxiety. Further, she accepted that for the same reasons her conduct towards the treating medical professionals was at times difficult and aggressive. As will be seen however, her acknowledgement has been general rather than specific and she does not necessarily accept the full extent of the findings sought.
- 10. Proceedings in relation to B and C were issued on the back of the proceedings in relation to A.
- 11. It is not alleged that they have been the subject of similar treatment to A, but that the mother's conduct in relation to their brother places them at risk of significant emotional harm at the very least.
- 12. That is a very brief summary of the issues at the heart of the fact finding exercise that the court has undertaken over the course of the hearing.
- 13. It is helpful at this stage to start with a summary of the extensive involvement that A has had with medical professionals, picking out some key issues and crucial dates in his treatment. This is by no means a complete and exhaustive chronology. The medical records in this case are vast running to over 10,000 pages. The court has been assisted by a detailed medical chronology professionally prepared by an independent chronologist, as well as detailed independent medical reports which have assisted with the identification of crucial incidents.

Medical background

14. A was born on 22nd June 2015 at 36 weeks gestation. By the time that he was 1 year old, concerns were being expressed about his development. He was found to have hearing loss and following genetic testing, he was diagnosed with 22q micro duplication syndrome. In the months that followed, A was admitted to Hospital A with complaints of diarrhoea and vomiting, which resulted in a diagnosis of cow's milk protein allergy.

- 15. In August 2017, just after A's second birthday, he was seen in a paediatric clinic at Hospital C, by Dr M a consultant paediatrician. The history given was that he was struggling to swallow. Intermittently he would refuse to eat. Following investigation by means of a video fluoroscopy(recording images as a radio opaque bolus is swallowed), he was shown to have a dysphagia or unsafe swallow for thick and thin fluids.
- 16. Following this diagnosis, he was admitted to hospital so that he could be established on a regime of feeding using a nasogastric tube ("NGT feeding"), which involved the introduction through the nose of a plastic tube which went past the throat and into the stomach to allow the delivery of nutrition. Over the months that followed, he seemed to tolerate the regime well, although there were reports of him pulling out the tube several times, so a decision was made to introduce a more permanent feeding method. He underwent surgery for PEG (Percutaneous Endoscopic Gastrostomy) on 21 September 2017 at Hospital B.
- 17. Eight days later, he was presented at hospital with redness around his gastrostomy but was discharged with antibiotics for a suspected local infection.
- 18. On 14 October 2017 his mother reported that he was screaming when fed. On examination his gastrostomy site was red with some granulation tissue (red or pink soft tissue formed in response to persistent inflammation around the gastrostomy site). This resulted in a 48 hour admission to hospital. He was treated with antibiotics and it was noted that his feeding tolerance was good.
- 19. A week later, on 21 October 2017, he was admitted to Hospital A with reported vomiting and feeding intolerance. It was also reported by the mother that A had not passed urine for 50 hours. This surprised the treating doctors since it did not fit with the clinical picture following investigation. Despite the history of vomiting, A appeared well hydrated and tests showed no signs of dehydration or kidney impairment. Investigation of the gastrostomy indicated it was in the correct position. Further, surprise was expressed by the treating doctors that it was being reported that he could tolerate feeding via the nasogastric tube but not by the gastrostomy. Both methods deliver feed straight into his stomach. During the admission it was recorded that the mother was described as "angry and frustrated and wanted to take him home as no one was doing anything" (G27).
- 20. In November 2017, A was readmitted to Hospital B as a result of reported poor gastric feeding tolerance and vomiting. He underwent an upper endoscopy (use of a thin scope with light and camera to examine the upper digestive tract) and laparoscopy (keyhole surgery to allow access to the abdomen). No obstruction was found. His balloon retained gastrostomy was changed to a Mick Key button (Low profile balloon retained gastric tube which sits at the level of the skin and allows the child to receive nutrition directly into the stomach). Since the investigation showed no mechanical reason for poor gastrostomy feeding the Consultant Paediatric Gastroenterologist at the Hospital B Dr R, suspected that A may be suffering from gastroparesis (a disorder in which the stomach does not empty food or liquid as quickly as it should). As result, it was decided to employ a Naso-Jeunal Tube (NJT) which again is

- introduced through the nose past the throat but bypasses the stomach and delivers nutrition into the small bowel. The theory is that if it avoids the stomach, it should reduce the level of vomiting.
- 21. This intervention was found to be tolerated well by A in that at a clinic review on 13 December 2017, it was reported that he was tolerating feeds administered in this way for 16 hours and gained weight.
- 22. On 16 December 2017, three days after the clinic appointment, the mother reported that A started vomiting yellow fluid several times a day and was passing stools up to 8 times a day. Testing indicated that the tip of the NJT was not in the stomach (thus it was correctly located) and so A was admitted to Hospital A in early January 2018 for further investigation.
- 23. Upon admission, A was not dehydrated and appeared well. The mother reported numerous vomits but initial investigations suggested that such episodes had not been witnessed by medical professionals.
- 24. During this admission it was reported that the Children's Community Nursing Team (CCNT) had raised safeguarding concerns since the number of problems reported by the mother relating to gastric feeding tubes splitting, falling out or problems with the gastrostomy balloon, far exceeded their experience of other patients in a similar position.
- 25. The treating paediatrician was concerned that the mother was anxious and struggling to cope. A was discharged home on 18th January 2018.
- 26. Due to what was described by Dr R as a perplexing presentation, it was suggested that an admission to hospital to observe symptoms may be called for.
- 27. There was a clinic review on 2nd February 2018 when it is said that the mother reported gastric losses of 300 ml per day. It was further suggested that she later confirmed 785 ml of gastric losses that day and 235 ml were lost in the gastric draining bag over the preceding 3 hours. The mother in her response document took issue with this but indicated that with hindsight perhaps she should have shown the treating staff the gastric bag which would have illustrated what she had seen.
- 28. Having confirmed by x-ray that the NJT was not displaced, this caused the treating team to be perplexed by the reported high level of losses. As a result of this, the medical staff suggested that A should be admitted to hospital but the mother would not agree to this.
- 29. On 8 February 2018, A was returned to Hospital A with a reported history of vomiting. He was examined, found to be well, noted to be tolerating his jejunal feeds and was discharged home.

- 30. On 19 February 2018, he was brought to hospital because he had pulled out Mic -Key button (low profile balloon retained gastric tube that sits at the level of the skin which allows children to receive nutrition fluids and medicine directly into the stomach).
- 31. The next day, A was presented at hospital once again with the mother providing a history of coffee ground vomiting, dark gastric aspirates and melaena (black tarry faeces containing partly digested blood as a result of upper gastrointestinal bleeding or the swallowing of blood). An x-ray at Hospital A did not show anything. A was transferred to the Hospital B. During his stay no dark aspirates or melaena were seen.
- 32. During the admission to the Hospital B between 25 February 2018 and 26 February 2018, the mother reported to nursing staff that A had vomited but this was not witnessed by staff. The mother suggested that she placed two blankets into the sluice but when the blankets were subsequently checked by nursing staff including staff nurse D, there was no evidence of vomit. The mother reported further vomiting at 7:20 AM on 26 February 2018. The mother now accepts that this was a false report and blames the untruth upon the fact that she was concerned and worried for A since he was so poorly and she wanted him to be checked by medical professionals to ensure he was "okay and comfortable".
- 33. The next admission of note occurred on 16th May 2018. A was admitted to Hospital A with a reported history of not passing stools for six weeks despite being on Sodium Picosulphate (Contact stimulant laxative used as treatment for constipation). During this admission he was easily treated using the same dose of laxative that had been available to him at home and it was noted that he tolerated gastric feeds. Once again, the history provided by the mother in relation to the extent of the reported constipation was questioned by the treating team due to the ease with which A was able to pass a stool following one administration of the laxative.
- 34. On 27 June 2018, A was reviewed in clinic and was tolerating gastric feeds well.
- 35. On 5 July 2018, A was seen in clinic by Dr K following the mother reporting that A had suffered seizures. It was recorded that the mother had not mentioned this to medical professionals before and there was no recorded information to indicate that any seizures had been witnessed by medical nursing staff during admission.
- 36. In October 2018 A was once more admitted to hospital. In July 2018, the G Jet or Gastro jejunostomy Tube had been converted back to a normal gastrostomy because he seemed to tolerating gastric feeds. On this occasion there was a history of vomiting and discomfort which was witnessed by the nursing staff. It was short lived and believed to be caused by a viral infection, something that was confirmed by subsequent stool cultures and thought may explain the increased vomiting in October.
- 37. It was decided due to the complex background and the mother's expressed concerns that A would not tolerate gastric feed that jejunal feeding was to be recommenced. There were difficulties inserting the Naso jejunal tube and A was transferred to the Hospital B for consideration to be given to the re-insertion of the G-Jet tube. This was done and he was discharged on 15 October 2018.

- 38. Unfortunately, he needed to be readmitted on 16 October 2018 since vomiting persisted. It was established that the G Jet needed reinserting and this was done.
- 39. At a clinic appointment on 28 November 2018, the mother again raised concerns that A was retching and vomiting on his naso jejunal feeds. Dr T in her safeguarding report makes reference to the notes of the clinic appointment with Dr M(G51):

"according to mother he was vomiting 3 to 4 times a day, bringing up 250 mL each time and was also draining about 600 mL of bile stained fluid in the gastric drainage bag. He was also not opening his bowels despite laxative doses being increased. He had been seen on the Day Unit earlier in the month when some faecal masses had been felt on examination and had a good result from the enema. He looked well in clinic despite the history of significant losses. Due to the history, Dr M arranged for blood tests and these were all normal confirming that there were no signs of dehydration. The history is likely to have been exaggerated as one would expect a child to be clinically dehydrated if vomiting 1000 mL per day and losing 600 mL in gastric losses. However, he looked well in clinic and bloods were all normal."

- 40. In February 2019, A had his Mick J reinserted. It dislodged and had to be reinserted on 21st February 2019 and 8 March 2019.
- 41. In April 2019 following a video fluoroscopy, it was concluded that A could safely manage thickened fluids. It was reported however that the mother was reluctant to follow this advice and indeed the subsequent history indicates that this was not progressed until A was admitted hospital following the instigation of care proceedings in August 2022.
- 42. At this time A had also been referred for a special sleep system bed by Dr M since the mother had reported A did not sleep well and repeatedly banged his head in bed. Dr T did not identify occasions from the clinical notes which identified these matters as being an issue when A was in hospital.
- 43. On 30 June 2019 A was seen again at the Paediatric Day Unit with reported concerns that feeds were coming back around the G-Jet tube. He was fed gastrically with medication through his jejunal port. The doctor on duty decided to commence A on Dioralyte (Oral hydration solution to replenish electrolyte loss following acute diarrhoea). It is recorded that the mother was angry and abusive to staff saying that A was starving and in pain. This appeared to contradict the observations of the treating staff who referred to him as being bright, alert and happy.
- 44. When seen at home by a dietician in July 2019, it was recorded that A looked well as gaining weight and indeed the mother had increased his feeds because he was tolerating them well. The mother still expressed some reluctance, it is alleged, to A having a trial of oral fluids. On this subject Dr T indicated in her safeguarding report "A would likely have been able to tolerate thickened fluids at this time and this may have reduced reliance on feeding tubes and associated problems."

- 45. A was readmitted to hospital on 1 September 2019 with the mother providing a history that he was not tolerating his feed via the gastric tube. The treating doctors once again regarded this as a perplexing presentation since he had tolerated gastric feed since February 2019 and there was no explanation why he would not tolerate them now. During this admission the tube was changed to a gastric tube instead of a G-Jet Tube since it was believed that this should not affect tolerance to feed. The record of this admission notes that gastric feeds were restarted and he tolerated continuous feed down the gastrostomy without any documented vomiting or problems with the feed. Dr T commented that despite now being transferred to the Hospital B for reinsertion of the G-Jet on 3 September 2019, A had tolerated gastric feeds for almost a year but despite this the jejunal tube was reinserted.
- 46. A review of A at school on 16 September 2019 noted he was doing well at school. He eats whilst there and there was no history of any vomiting at school. Once again attempts were made to encourage the mother to retry oral fluids but Dr T records the mother remained reluctant and thus this did not occur.
- 47. On 9 January 2020, A was reviewed in clinic by Dr L, Consultant Paediatric Gastroenterologist at Hospital B. At this appointment it is noted that the mother reported a poor gastric feeding tolerance for the past few months and that there was a need to revert to jejunal feeding. It was also recorded that A continued to eat at school and there have been no reports of vomiting whilst he was there.
- 48. Two months later, on 7 March 2020, A was admitted to hospital once again with a history of vomiting and not tolerating his feeds. He was found to have Influenza A infection. It was agreed to replace the Mic-Key (balloon retained gastric tube) with the Mick J (Mic Key with an internal tube) and feed A jejunely when he was unwell.
- 49. Over the next three months, A was reported to tolerate gastric feeds, was eating well and was following the 50th centile.
- 50. Due to the Covid 19 pandemic, on 15 June 2020, A had a telephonic review with the team at Hospital B. The mother reported that she had reverted to jejunal feeding due to A vomiting and the frequent need to change the Mick- J due to the gastric balloon bursting. A was referred to the surgical team at Hospital B and a direct jejunostomy (the surgical creation of an opening to the jejunum through the skin at the front of the abdomen). He was discharged home with jejunal feeds on 20 July 2020 with a plan to transition him back to gastric feeds.
- 51. Unfortunately, on 31 July 2020 A was readmitted because his jejunostomy had dislodged. It is recorded that during this admission the mother was resistant to allow A to be fed either gastrically or jejunally and he had intravenous fluids only. As a consequence of this, it was recorded that his blood sugar dropped. It is noted that there were difficult interactions between the mother and medical professionals with her being described as being verbally aggressive. It is suggested that the mother accused doctors of "trying to kill him". A was eventually discharged on 26 August 2020. In her safeguarding report, Dr T recorded the following

"during this admission, the mother contacted Hospital A Nursing Team saying know was unable to tolerate feeds down the jejunal tube and that he needed a central line and there was a possibility of him being referred to the Great Ormond Street Hospital. In my opinion this is manipulation of the information and misrepresentation of the situation. He did require an intravenous line and he did drop his blood sugars, but this was felt to be secondary to him not feeding rather than an intrinsic problem with the way he managed his blood sugars. Mother was refusing to allow the surgeons to feed him down his jejunal tube or his gastric tube and this resulted in his blood sugars dropping and a need for intravenous fluids".

- 52. Further concerns were recorded at a review with the dietician on 4 September 2020. It was noted that A had gained weight however the dietician noted that the calories that he was receiving from his enteral feeding plan were below the requirements for growth and therefore he must have been eating more than the mother was saying. The dietician alleged that the mother told her A was not eating anything. The concern was that this did not fit the clinical presentation. The calorie intake from the enteral feeding alone would not be sufficient to enable growth as well. This was believed to be a further episode of the mother misreporting facts or exaggerating the position.
- 53. A was admitted to Hospital A again on 1 October 2020 with a jejunostomy infection. A was given IV antibiotics but a plan to change the treatment to enteral antibiotics was blocked by the mother said she believed he would not absorb them. During this admission A required several cannula placements and his jejunostomy was found by his mother in his bed. This had occurred despite the tube being dressed and taped to the skin.
- 54. On 1 December 2020, a Port a Cath (a central venous access device used to draw blood and give treatments including intravenous fluids sited in chest under the skin) was inserted. A was once again discharged home.
- 55. Within a few days on 7 December 2020, during a review with the dietician on the telephone, the mother reported numerous episodes of vomiting. A was reported to be in pain and it was suggested that he should be brought to hospital. The mother resisted this suggestion initially. At a further review with the dietician on 23 December 2020, the mother is said to have reported A was in pain and pulling his knees up during this feed with increased drainage into his gastric drainage bag. She was advised to change his feed and to bring him to A&E if there was no improvement. The dietician SD contacted the mother again on 24 December 2020. The mother reported that A symptoms had not improved and she was advised to take him to hospital. The mother in her threshold response indicated that she was of the opinion that since it was so close to Christmas and there was likely to be a skeleton staff that it was unlikely that anything more would be done for A over the Christmas period.
- 56. In any event she eventually took A to hospital on 29 December 2020. On admission the reported concerns were of vomiting, milk drainage from the gastrostomy and crying in pain when jejunally fed. On admission it was recorded that A looked happy and not dehydrated. The jejunostomy site looked as if it may be infected. A was given 540 ml jejunally over 3 hours after which there were 700 mL in his gastric drainage bag. Despite an x-ray showing

- the jejunostomy to be correctly placed, it is recorded that the mother refused for it to be used and requested a second opinion.
- 57. As a consequence, a referral was made to Hospital D and A was transferred on 5 January 2021.
- 58. He remained an inpatient in Hospital D for 15 days until 20 January 2021. Whilst there he was diagnosed with a small intussusception of the bowel. (telescoping of the bowel secondary to the jejunostomy procedure) This may have caused pain. Dr RA the treating consultant was at a loss to explain the pattern of alternating gastric feeding intolerance. The mother indicated that these episodes coincided with constipation. In light of this a more aggressive constipation management plan was to be trialled.
- 59. By the time that A was transferred back to Hospital A on 20 January 2021, it is recorded that A was placed under closer monitoring since a suspicion of Fabricated/Induced illness had been raised. The mother expressed an unwillingness to see any other doctor than Dr T and it is recorded that she was reluctant to follow medical advice. During admission A was offered and happily took oral food and was discharged on 8 February 2021. His mother was provided with suppositories to be used if he had not passed stools for three consecutive days.
- 60. When seen at home by the dietician 10 days later, A was well. He was eating three meals a day and receiving 16 hours of jejunal feeding and not using gastric drainage bags. There were no reported problems with constipation and it was hoped that gastric feeding could restart at the next review.
- 61. At the next review on 14 April 2021, the mother reported a history of nocturnal vomiting for which a gastric drainage bag at night was used. At the subsequent review in June 2021 the mother suggested that A's gastric tolerance had deteriorated and gastric drainage bags were used at night.
- 62. A further video fluoroscopy was undertaken in July 2021 and this indicated that his swallowing difficulty had resolved with him now being safe to swallow thin fluids.
- 63. On 22nd August 2021, he was admitted to hospital for a gastrostomy infection and was placed on IV fluids due to the reported history of vomiting. He was discharged but the following month on 28 September 2021 he was again admitted to hospital due to the mother reporting poor jejunal feeding tolerance. When admitted he was found to have an infected jejunostomy site.
- 64. A Multi-Disciplinary Team meeting was convened involving the medical and surgical teams at Hospital B and Hospital A. The conclusion of this meeting was that the medical professionals did not believe that A had gut failure and that his presentation was not typical of gut dysmotility. There was no clinical reason why he should not be able to tolerate gastric feeds and it was concluded that the surgical tube(jejunostomy) needed to be removed as soon as possible as this seemed to be causing all the problems. It was agreed he should be admitted to hospital for this to be achieved.

- 65. A remained an inpatient between 6 October 2021 and 21 January 2022. He was extensively investigated but no cause for his poor feeding tolerance was found.
- 66. On discharge, he was to be fed 60 mL blended diet via gastrostomy twice a day and jejunal feeding over 15 hours each day.
- 67. Following his discharge, there continued to be concerns about the mother's reports of poor gastric tolerance and the evidence of other independent agencies such as the school who reported that A was eating well orally.
- 68. On 28th June 2022, A was admitted to hospital with a dislodged Naso Jejunal Tube.
- 69. What appears to have been the tipping point for Dr T and the treating team was the MDT meeting on 13th July 2022, when the mother attended the feeding clinic. Present was Dr T, the Dietician and the Speech and Language Therapist. It is instructive to quote from the report of Dr T.(G42) at paragraph 6.88 onwards:
 - "mother walked into the clinic room and announced that she thought that the nasojejunal tube was probably in his stomach, she said A had been unwell overnight and when she aspirated the nasojejunal tube, she got wotsits and milk backup. She told us he was uncomfortable with this but there was no vomiting. I clarified that she continued to give him 75 mL of milk for a few hours at least the night, this was despite knowing the fact that the jejunal to was likely in the stomach. She said he was a little bit unsettled but had not had any significant vomiting. On examination in the clinic, A appeared well in himself. He was happy, bright and alert despite the history of being fed 75 mL an hour into his stomach. We confirmed the nasogastric jejunal tube was in fact in the stomach
 - 6.89 . This is extremely concerning behaviour as mother has knowingly fed him despite thinking the tube was discharged in the stomach. This is on a background of her previously not allowing us to reinstate gastric feeds or antibiotics and obstructing medical staff during admissions when the plan is to do this. I was concerned at the time that this represented evidence of fabrication of illness and possibly attempt at induction of illness. The only explanations are either mother knows that he can tolerate gastric feeds and therefore continue to give it overnight until she came to clinic or mother was trying to induce illness as she did not think he could tolerate gastric feeding but continued to give the feed despite knowing the tube was likely to be in the wrong place.
 - 6.90 I explained to mother that given this history, we now needed to bring him into hospital for a formal reintroduction of gastric feeding. Mother became very aggressive and abusive during the clinic and refused to try any gastric feeding. She threatened that if he became ill it would be my fault.
 - 6.91 In my opinion there is no reasonable explanation for this response except mother is portraying A as being sicker than he is and reliant on tube feeding he does not need. Mother has told us he tolerated gastric feeds overnight but refuses to let us try in hospital."
 - 70. Following the clinic appointment, Dr T contacted Dr C at the Hospital B. They discussed their concerns and it was agreed that evidence would be collated and a referral made to Children Services with a view to facilitating a medical assessment of A without the mother

being present for at least two weeks to ensure that he tolerated gastric feeding. Dr C agreed with this course of action and on 17 July 2022 as a result of A's nasogastric tube being displaced, he was admitted to the Hospital B.

- 71. Dr T detailed areas which caused her concern
- 72. It is helpful to summarise them:

<u>Summary of radiological interventions</u>: at least 96 radiological investigations. These primarily relate to checking tube positions. High number of tube dislodgements and problems with tubes blocking. Complications with tubes are not uncommon but the number in A's case are high. No witnessed behaviour when A was an in-patient playing with this tube or pulling out his tube. Dr T suggests all tubes have either fallen out at home or during inpatient admissions when the mother has been in the room or on her own with A. This does not mean all incidents have been manipulated but the history presents a concern.

Social and developmental concerns. A attends primary school. He does have a developmental impairment. He enjoys school. The school indicates he is able to eat normally at school and does not struggle with significant vomiting. Due to repeated admissions, A has missed a significant amount of school. This has impacted on his learning and development. The mother's conduct by behaving aggressively and abusively towards medical staff in front of A will impact on him emotionally. The amount of time spent in hospital which may have been unnecessary in large part, has caused him to miss out on socialisation and developmental opportunities. Potential delay in toilet training.

73. Dr T in her safeguarding report then referenced her findings to the updated Guidance from the Royal College of Paediatrics and Child Health in February 2021 "Perplexing Presentations and Fabricated /Induced Illness in Children." She listed the areas of concern under various headings detailed in the guidance:

Alerting features in the child

Reported physical, psychological, behavioural symptoms and signs not observed independently:

- a. Mother reporting vomiting and distress on numerous admissions which has then not been seen in A has been admitted to the ward.
- b. Mother reported increased gastric losses which were not observed on the ward.
- c. Mother reported seizures and A was investigated for these. These were never witnessed or raised during any admissions or at clinic appointment with his paediatrician.
- d. Mother reported to geneticists that A had significant headbanging and injuring himself, however this has never been seen when A has been admitted to hospital.
- e. Mother has reported A having bloody aspirates and melaena not documented on admission.

f. Despite laxatives mother gave a history of A not opening his bowels for six weeks, however on admission to hospital he had one extra dose of laxative at a very small dose and had a large amount of stool passed that night.

Unusual results of investigations:

- a. On admission on one occasion mother alleged A not passed urine for 50 hours. This history resulted in blood tests, urine tests and scans. All results were normal which would be highly unlikely in a child who had not passed urine for 50 hours.
- b. Mother reporting A not tolerating jejunal feeds on several occasions and vomiting milk back. Numerous investigations including x-rays and blue dye test showed the jejunal Tube was correctly positioned and not blocked.

Inexplicably poor response to prescribed treatments

a. History provided by mother of poor sleep despite melatonin prescription. Poor sleep has never been reported during A's numerous admissions. A weaned off this medication during two week period of observation and admission and he slept well with no problems.

Some characteristics of the child's illness may be physiologically impossible

a. Reports by mother of A having large amounts of milk aspirates or water into the gastrotomy drainage bag on several occasions despite jejunal tube being in correct position and not being blocked. If jejunal tube was in the correct position and being used to supply milk, it is not possible for milk to be draining into gastric drainage bag.

<u>Unexplained impairment of child's daily life including school attendance and social</u> isolation:

- a. The issue of the amount of school missed due to medical investigations.
- b. A often brought to hospital in a wheelchair. Although he has an abnormal gait he is fully mobile.
- c. Issues with sleep not witnessed by treating team.

Alerting signs in parental behaviour: parents insistence on continued investigations instead of focusing on symptom alleviation when reported symptoms and signs not explained by any known medical condition in the child:

- a. Mother has requested second opinions and further investigations and has refused to allow doctors to act in A's best interests and this has resulted in A requiring more intervention than is felt to be needed.
- b. The mother refused to allow surgeons to feed him down the gastric or jejunal feeding tube, which resulted in an escalation of care and need.
- c. On several occasions A has been reported to be doing well and the medical team have planned to restart feeds. The mother has then given a history of him not tolerating jejunal feeds and high gastric losses. This resulted in A being kept on jejunal feeds longer than necessary.
- d. A's jejunostomy was probably not necessary since he appeared to be able to tolerate gastric feeds most of the time.

Parental insistence on continued investigations instead of focusing on symptom alleviation when results of examination and investigations have already not explained the reported symptoms or signs:

a. Despite investigation showing that the jejunal and gastric tubes have been in the correct position, the mother refused to allow gastric feeds or even jejunal feeds. This has resulted in prolonged admissions and a requirement for intravenous fluids.

Repeated reporting of new symptoms:

a. A was investigated for possible epilepsy due to a history of seizures, however these were never witnessed by medical or nursing staff.

Repeated presentations to and attendance at medical settings including emergency departments:

a. A has been repeatedly presented with failed gastric and jejunal tubes. Although recognise that complications of enteral feeding tubes can occur, A appears to have had a significantly high number of affected gastrostomy tubes, jejunal tube and surgical jejunal tubes. Surgical jejunal tubes are particularly difficult dislodge or to cause to fall out accidentally as they are taped into the skin.

Inappropriately seeking of multiple medical opinions:

- a. In December 2020, the mother contacting dieticians at Hospital B and Hospital A providing a history of A not tolerating feed and vomiting all the time. Failure to contact medical staff to bring A to hospital until she was advised to do so by a consultant.
- b. Mother refused to allow the team at Hospital B to be involved in his care leading to a referral to Hospital D in January 2020. This was not in A's interest as the Hospital D did not have all his past information and it was suspected that the mother's motivation for opposing admission to Hospital B was that hospitals previous indication that A did not need any intervention and had refused IV feeds in the past.

Parents not able to accept reassurance on recommended management and insistence, more, clinically unwarranted, investigations, referrals, continuation of, or new treatments (sometimes based on Internet searches).

- a. This was a major concern in this case and the mother's behaviour towards staff has impacted on their decision-making.
- b. Initial impressions were that maternal anxiety was impacting on mother's ability to allow doctors to treat A. Doctors initially attempted to encourage the mother to address this issue with early help support and suggesting she see her GP. The mother refused this.
- c. Overall, there have been several occasions when mother has refused to allow doctors and surgeons to carry out investigations that they believe A needs and will tolerate and had become aggressive and abusive towards doctors, nurses and surgeons both at the Hospital B and Hospital A. This has resulted in A having

- prolonged periods of time in hospital and unnecessary intravenous fluids which has resulted in numerous cannulas and ultimately the insertion of a Port a Cath due to difficult intravenous access.
- d. Despite normal video fluoroscopy results for thickened fluids orally in April 2019, mother refused to allow A to be tried on thickened fluids.

Frequent vexatious complaints about professionals

- a. Mother has frequently made complaints and threats to take A to other hospitals halfway through his treatment. During admissions at Hospital A and Hospital B mother has refused the doctors to come into the room and on occasion has refused to speak to certain doctors.
- b. Mother has said she will make a formal complaint to Hospital B on several occasions.

The proceedings

- 74. So, this was the long and troubling history which brought this case to court and to an urgent hearing which I dealt with on 22nd August 2022. At the time of the hearing A was an inpatient at Hospital B.
- 75. Because of the fears of the local authority that the mother may try to remove A from the ward and that he may be at serious risk since the mother would not be able to provide A with hydration nutrition at home, the local authority sought to persuade the court that the mother should not be given notice of the proceedings. They also pointed to the fact that on 12 August 2022, whilst A remained an inpatient at Hospital B the mother stated she was going to take A home and only refrained from doing so when it was indicated that the police may be invited to exercise their powers of protection, that she did not do so.
- 76. In short, the local authority at the instigation of the treating medical team wished to facilitate a period of observation in hospital of A when his mother's access to him was restricted so that an objective picture could be obtained about the true situation as to what A could tolerate in terms of feeding and to what extent the conduct of his mother was impacting upon his well-being.
- I expressed the view that seeking an order without giving a parent notice was an extreme step. I also indicated that I was not sure that an *ex-parte* interim care order was in fact a remedy known to law. I took the view that the mother should be given short notice of the application for an interim care order and the hearing was listed later on the same day.
- 78. The mother was able to secure the services of Ms Phoenix, a very experienced and capable solicitor, to act for her at short notice.
- 79. I heard limited submissions from the parties and decided to make an interim care order with a view to considering the application more fully the next day. In the meantime, I indicated that A would remain an inpatient at Hospital B and that the mother should not undertake any aspect of A's care and feeding until the court further consider the case.

- 80. The case returned to court the next day on 23 August 2022. By this time, Dr B, the clinical lead at the Hospital B had confirmed that the mother would need to be fully supervised during the assessment process to preserve the reliability of the assessment. The mother agreed in principle to the assessment, but sought to remain with A during the assessment, accepting that she would not be able to undertake A's care. She was at pains to stress that she had not caused any harm to A and stated she would not do so.
- 81. I determined that the case should be further adjourned so that a joint statement could be prepared by the medical professionals to allow the court to consider the proportionality of separation of A from his mother and the appropriate level of contact or supervision during the assessment period.
- 82. By the time the case returned to court on 25th August 2022, the court was in possession of a joint statement from Dr B and Dr T. In short, they indicated that they needed to get an accurate picture of A's feeding behaviours and ability to tolerate feed were not influenced by his mother's presence or behaviour. They indicated his inability to tolerate gastric feeding, especially when he is able to take food orally, did not make medical sense and the mother's presence would be obstructive to any objective appraisal.
- 83. At the hearing on 25th August 2022 having heard submissions, I approved the local authority plan for a two-week assessment. During this period, the mother would have no contact with A overnight or between 9 AM and 3 PM and that any contact that she did have was to be fully supervised. I directed that at the conclusion of the assessment Dr T was to prepare a report and a detailed medical chronology. I listed the case for review on 9 September 2022 to look at the contact arrangements and then a more extensive review following the receipt of Dr T report on 20 September 2022.
- 84. I have already referred extensively to the child protection report of Dr T dated 13 September 2022 in terms of her overall appraisal of the history. However, this report also provided an appraisal of the two-week assessment authorised by the court at the hearing on 25th of August 2022.
- 85. In summary, the report raised the following points of relevance arising from the assessment, which ran from 24th of August 2022 when he was returned to Hospital A until 11 September 2022:
 - a. A had a feeding regime of 150 mL of milk and 150 mL blended diet. The feeds were all via gastrostomy, with the Naso jejunal tube having been removed prior to transfer.
 - b. During admission when the mother only had supervised contact, A managed to eat and drink normally. There was no history of significant vomiting, retching or abdominal pain. When he was allowed to drink, he drank well and was keen to drink. This was unusual for a child who had been nil by mouth orally for a long time and raised the possibility of him already having drinks at home.

- c. There was no evidence of aspiration clinically. He was eating normal food although sometimes only half portions.
- d. He was noted to play all day and be "on the go" all the time. He had a good bedtime routine and slept well in a normal bed. He was weaned off and stopped all his medication for sleep with no adverse effects.
- e. During the admission A did not touch his gastrostomy tube or pull at it. This ran contrary to the mother's previous suggestions that A would do this.
- f. A was a happy sociable boy who was not significant distress without his mother being present. The nursing staff reported that his verbal communication has improved significantly during the two-week assessment.
- g. Nursing staff who knew A from previous admissions described how he was like "a different child". On previous admissions he would spend long periods on his iPad or in bed or in his wheelchair when mother was present. He is now up and about on the ward all day, engage with play specialists, nursing staff and other children in the playroom. He only takes his wheelchair for long walks around hospital and often does not use it for the whole journey.
- h. A was having gastrostomy feeds to top up his oral intake to maintain his weight. He tolerated these feeds with no problems. He had no problem with low blood sugars in hospital.
- 86. There was one issue which caused concern. On 2 September 2022 his gastrostomy tube was snapped at the end that connected onto the feeding pump. This was noted by the nurse looking after A when she went to feed him at 5 PM. She noticed the tube was leaking. The same nurse had given the 2pm feed and had not noted a problem. It was recorded that the mother was with A between 3 and 7 PM that day. Dr T noted in her report that the mother indicated when told that advice should be sought about a repair of the tube from Hospital B".
- 87. Dr T expressed concern about this incident as follows(G53):
 - "we have since inspected the extension and note that the hard plastic part of the tube has been snapped in two. This could not have been done accidentally by A by him leaning or kneeling on it as it only reaches to his abdomen. A does not in my opinion have the dexterity to snap the tube himself. The nursing staff have not noticed any fault with the tube. Therefore, in my opinion, the only explanation is that somehow during contact the tube has been snapped deliberately. I am concerned that mother presumed that when the tube snapped, he would need to go to the Hospital B. This is extremely concerning and suggests that the mother may have been trying to sabotage the assessment"
 - 88. By the time of the hearing on 20 September 2022, a positive viability assessment of the maternal grandfather and his wife have been undertaken and the plan was that A should be discharged from hospital into their care. Provisions for contact to the mother were put forward which provided for three sessions of 90 minutes contact between Monday and Friday on one session of three hours at the weekend. All contact was to be professionally supervised and the extended weekend contact was to include siblings.

- 89. At this hearing I also approved the instruction of a consultant paediatric gastroenterologist, a consultant paediatrician, an adult psychiatrist and a child and family psychiatrist. I did not approve the instruction of an independent geneticist since it did not seem to me that such additional expertise was necessary.
- 90. A was reviewed by Dr T at her clinic on 9 December 2022. By this point A had been in the care of the maternal grandfather and his wife for three months. The clinic letter contains the following paragraph which summarises Dr T appraisal of A's progress:
 - "I am pleased to say that he is doing well. The carers had no significant concerns about him except that he appears to get fixated on certain foods. Currently it is pasta and all he will eat is pasta although he is having variations of this including spaghetti Bolognese lasagne and cheesy pasta. He will also have pizza and turkey dinosaurs. There are no reports of choking or gagging on any of his food. He has vomited on four occasions since he has been with his new carers although they feel this has been when he has had a lot to eat and, in their words, "made a pig of himself!" It is excellent to see A is enjoying food and thriving in his new environment."
 - 91. Dr T in a statement prepared on 13th March 2023, Dr T recorded that A continued to make good progress with the maternal grandfather and his wife. There was no evidence of recurrent infections of the gastrostomy site and there had only been one visit to hospital when A attended A&E with a history of a persistent cough which caused him to be sick and off his feed. Other than that, there was no history of vomiting or an inability to tolerate gastric feeding. He is also eating well. The plan is to remove the gastrostomy tube and replace it with a gastrostomy button and to remove the Port a Cath which is not required and brings a risk of infection. In short, the position was markedly different to the one which confronted the court in August 2022.
- 92. Despite the late filing of the report of the independent consultant paediatrician Dr Ward, the case has progressed to a point whereby it was ready for final hearing on 13 March 2023.

Independent expert reports

- 93. As is common practice in these cases, independent expertise is required to assist the court in appraising the medical position and reviewing the extensive medical history of this child.
- 94. The court has also been assisted by the preparation of a detailed medical chronology.

Dr Camilla Salvestrini, Consultant Paediatric Gastroenterologist, Report 29/12/2022, addendum reports 3/3/2023, (slightly amended main report 13/3/23)

95. Having considered the extensive history, Dr Salvestrini reached the following conclusions:

Feeding difficulties:

a. A was diagnosed with an unsafe swallow (dysphagia), in 2017 when he was two. He could not swallow safely so needed a nasogastric tube replacement. It is not

unusual for a toddler to pull out a NGT on numerous occasions. As a result, a gastrostomy was placed. Subsequent video fluoroscopes indicated that his dysphagia had resolved. The mother was not prepared to allow his feeding to progress to oral intake. By refusing to do so, the mother has hindered the normalisation of his nutrition and on balance has not acted in his best interests and cause him harm.

Gastrostomy infections:

a. Between 2017 and 2022, the Community Nursing Team noted 10 infections, with a further two noticed at admission in 2021. Gastrostomy site infections are rare in children with a normal immune system, when the site is appropriately cared for. The advice is to clean the site daily. If infection is active, the gastrostomy site widens and therefore leaks gastric content onto the surrounding skin. The decision to progress to a surgical jejunostomy was driven by recurrent dislodgements and site infections. The procedure could have been avoided entirely if A better gastrostomy site care. As a consequence, A suffered significant harm, namely pain and discomfort, numerous antibiotic treatments, some of which were intravenous as an inpatient and an escalation to direct jejunostomy

Vomiting

- a. A had no history of significant vomiting before 2017. Following the diagnosis of his unsafe swallow, he was NGT fed for three months. There was no evidence of significant vomiting. In October 2017 he was sick due to a viral infection. The mother appeared to ascribe the gastrostomy as the cause. The delivery of gastric feeding with NGT or Mic Key button should make no difference since both feed into the stomach in the same way. During this first hospital admission for vomiting, the symptoms reported by the mother of persistent vomiting, lack of urination for 50 hours was not observed by treating staff. Dr Salvestrini suggests that the decision at Hospital A at this time to pass a NJT may have reinforced the mother's view that PEG feeding was the problem.
- b. The decision to start A on jejunal feeding was based on a suspicion of gastroparesis. There was no strong evidence of this and other things should have been tried first. The decision at Hospital B to escalate to jejunal feeding also corroborated the belief of the mother in relation to the use of the gastrostomy. From this point, episodes of reported vomiting escalated despite jejunal feeding. Such symptoms were not witnessed in hospital (p.10 of the addendum report lists the non witnessed incidents of vomiting). Due to these reports, he remained on jejunal feeding for a long time and was subjected to a Mick J placement. On balance, the vomiting episodes were overreported, exaggerated or fabricated on most of the occasions, and the high gastric losses were exaggerated or fabricated. The poor feeding tolerance was therefore fabricated exaggerated. As a result, he has been significantly harmed by being subjected to invasive procedures, radiological exposure, hospital admissions and being delayed in oral intake reintroduction.

Direct jejunostomy problems

- a. A had several episodes of his jejunostomy tube being pulled out. On balance this was due to a lack of attention in dressing and handling it.
- b. The jejunostomy got blocked a few times with medications. This is a known complication due to the small bore of the tube. Administering medications in this way is only indicated in cases of severe gastric dysmotility which A did not have. He could have tolerated his medication gastrically in the same way he was able to tolerate his food gastrically. The mother's refusal to allow medications to be delivered gastrically caused harm because A then needed either IV treatment or repeated tube changes associated with periods of decreased feed.
- c. Further at the end of 2020, A had a small intussusception around the direct jejunal feeding tube. This is a direct complication of this feeding tube. On balance, it was responsible for a period of abdominal pain, bilious vomiting and poor feeding tolerance at the end of 2020. Thus, the decision to have a jejunostomy which was directly related to the mother's conduct and caused harm.
- d. During the admission for this surgery in July and August 2020, the alleged refusal of the mother to the commencement of jejunal feeding ended up with A needing IV fluids and being starved.
- e. In her addendum report, the doctor expressed the view that jejunal feeding was in all likelihood never required and there is no clinical evidence in A's case to confirm he needed to move to jejunal feeding.

Mick J Dislodgement and bursting of balloons

- a. A had 13 radiological procedures to replace Mick J in 2019 to 2020. In addition he had several episodes of the Mick J balloon bursting. This level of dislodgements is unusual. The balloons are susceptible to yeast infection which may cause them to burst, but on the balance of probabilities the timeframe is too short for an alleged infection to weaken the device
- b. In answer to additional questions, Dr Salvestrini commented that this level of dislodgement and balloon bursting was exceptional in her experience of 19 years of looking after tube fed children.

Intermittent feeding intolerance

a. Between 2017 and 2022 A has had intermittent issues with feeding. This is both gastrically and jejunally. Whilst intercurrent infections may cause vomiting, the consistent problems reported while at home compared to the feeding tolerance in hospital can't be explained. It is unlikely that all episodes coincidently resolved at admission to hospital. Over the years A has been eating orally and tolerating it. It is not possible to explain via evidence based medicine by A needed jejunal feeding while orally fed.

Constipation

a. It was suggested by mother, that A had not passed a stool for six weeks. Children who are jejunally fed do not have to pass stools regularly as there is not much residue in their feed.

b. Six weeks without bowel motions and not in keeping with no symptoms of abdominal distension or abdominal pain. When A did have clinical signs of constipation it responded well to treatment despite the same treatment being reported as ineffective at home. On the evidence, A had mild constipation and episodes of vomiting but not sufficiently severe and persistent to require jejunal feeding for so many years. The reported severe constipation namely six weeks with no bowel motions, was on balance exaggerated or fabricated and this led to unnecessary hospitalisation and treatment.

96. At page E35 of the bundle, Dr Salvestrini reached this overall conclusion

"A did have dysphagia for thin and thickened fluid in 2017. Over time though, his dysphagia improved and finally resolved by June 2021. During this time, he had some oral intake, but his mother refused to let him have thickened fluids first and thin fluids after 2021. On balance of probabilities, should he have had access to oral fluids, he would not have needed prolonged tube feeding and therefore all complications and problems he had around feeding tubes (infections, replacements, dislodgement, surgery, radiology, intussusception). A has been dramatically harmed by the resistance to implement fluid intake at the time it was suggested and by the refusal to advance with his feeding plans when advised to"

Dr Kate Ward, Consultant Paediatrician Report 7th February 2023.

- 97. Dr Ward produced a detailed report complete with an extensive medical chronology which ran to some 263 pages. The key conclusions of Dr Ward's extremely thorough review of the medical information held in relation to A is as follows:
 - a. 22q11.2 duplication syndrome explains A's learning and language problems and moderate sensory neural hearing impairment. It is possible it was responsible for the unsafe swallow for liquids diagnosed in early childhood. It is difficult to say if it contributed to gastro-oesophageal reflux and cow's milk protein allergy since these are common in the general population. A's underlying problem may have contributed to his perplexing presentation, but was not its sole cause. The discrepancy between what the mother reported and what was witnessed by medical professionals is concerning. When supervised in hospital he made significant progress was able to eat and drink normally with no significant vomiting, retching or abdominal pain.
 - b. The history of intermittent vomiting and feeding tolerance associated with jejunostomy and gastrostomy feeds is not consistent with cow's milk protein intolerance.
 - c. There is no support for a diagnosis of intestinal dysmotility.
 - d. Although constipation is a feature of A's presentation, it would not explain the severe episodes of feed intolerance and vomiting.
 - e. A had frequent granulation and infection affecting the jejunostomy and gastrostomy sites. The mother was offered appropriate support and management. The mother had a low threshold complaint which, at times lead to escalation of treatment, e.g. refusal to accept oral antibiotics which led to intravenous treatment. This caused A significant distress as a venous access became difficult.

- f. There has never been an indication for parenteral nutrition in A with no clear documented evidence of feed intolerance and although there were fluctuations in weight, overall, he maintained a steady growth velocity.
- g. The mother has described episodes of severe vomiting, retching, abdominal pain and other symptoms. On occasion records do not confirm the mothers account of volume or frequency of vomits. On other occasions there are discrepancies and exaggerations. Sometimes descriptions which have been physiologically impossible e.g. a full gastrostomy bag would not be compatible with feed coming back from the jejunostomy when the dye test was negative. There is a suspicion of tampering with equipment but the evidence remains speculative. Tubes and needles do become dislodged accidentally but the number and circumstances of events in this case is concerning, especially in light of the mother's reluctance to comply with medical advice and in light of her intense criticism of the clinicians involved.
- h. On occasion the mother's actions were associated with significant risk to A. Refusing to allow enteral feeds when there was no venous access run the risk of dehydration. Threatening to leave the ward or discontinue treatment placed him at risk of harm. Witnessing persistent shouting and conflict is known to be traumatic for children and may have an adverse effect on emotional, physical and cognitive development in the long term.
- i. The claim that A had not passed urine for 50 hours was physiologically impossible and was shown to be so by tests. This assertion led to unnecessary investigations and interventions.
- j. Continuing to feed A via a jejunal tube which she believed to be displaced without seeking medical attention
- k. The mother is threatening and aggressive interaction with medical professionals alleging they were negligent resulted in A being exposed to many investigations and interventions which with hindsight were unnecessary.

98. Dr Ward ultimately concluded as follows:

"having considered the medical records, alongside the Royal College of Paediatrics guidelines, I agree with the treating paediatricians that this was a perplexing presentation and that the mother's actions went beyond those of an anxious parent, and that there is evidence of fabricated illness. I have not found evidence of induced illness"

The law

- 99. The parties have provided to the court an extensive summary of the current jurisprudence relating to such cases as this. I have considered that document and I accept it reflects the current state of the law. I think the principles stated in that document can be boiled down to the following statements of principle:
- 100. In relation to the findings of fact sought, I remind myself that the burden of proof is on the Local Authority. The standard of proof is the simple balance of probabilities. In other words, a fact is either proved or it's not; and if it is not proved, the court behaves as if that fact had never taken place. There is no room for speculation.

- 101. Next, findings of fact must be based on evidence, including inferences that can be properly drawn from the evidence, and not mere suspicion, surmise, speculation or assertion. The court can take into account a broad evidential canvas. This includes oral and documentary evidence. In this case this includes extensive medical records. The court is entitled to take into account hearsay evidence but must consider the provenance of that evidence and what weight can properly be given to it.
- 102. The court should not reach a conclusion on the veracity of a witness based purely on the performance in the witness box. The court must remember giving evidence can often be a challenging and stressful experience. It is, however, permissible to factor in a witness's demeanour and performance in the witness box as part of an overall appraisal of the evidence and whether it is reliable or not. The weight to be attached to demeanour will depend on the specific facts and circumstances of the individual case.
- 103. There is no obligation on a party to prove the truth of an alternative case put forward by way of a defence, and the failure by a party to establish the alternative case on the balance of probabilities does not prove the Local Authority's case without more.
- 104. I remind myself in relation to the issue of lies told by witnesses, that I should take account of the revised direction referred to in legal terms as a *Lucas* direction. Thus, I should only take into account a lie told by a witness if I am satisfied that there is no innocent reason for the witness to have lied in his or her evidence; and that it is germane to a serious issue which needs to be determined in the case. The mere fact of a lie being told doesn't prove the primary case against a party or witness who's been found to have lied to the court, but is capable of amounting to corroboration with regard to a particular allegation. In any case where a lie is said to be relevant the advocate seeking to rely on the fact a lie has been told must identify: (i) the deliberate lie(s) upon which they seek to rely; (ii) the significant issue to which it/they relate(s), and (iii) on what basis it can be determined that the only explanation for the lie(s) is guilt.
- 105. This case involves expert medical opinion. The court must give proper consideration to this evidence and is entitled to rely on expert opinion. Such evidence must be viewed in the factual context of the case as a whole. The court can depart from expert opinion but should explain the reasons for doing so. Ultimately it is for the court to decide the outcome of the case and not the experts.
- 106. The court must entertain the possibility that medical evidence may not always explain a child's presentation. The current state of medical knowledge is not finite and future developments in science and medical knowledge may undermine what was previously regarded as medical fact. An unexplained cause must always be considered.
 - 107. I have been referred specifically to <u>Re 5 Children (Induced and Exaggerated Illnesses Pattern of Behaviour) [2021] EWHC 3750 (Fam),</u> a relatively recent decision of Williams J in which he discusses the correct approach to such cases with reference to the 2021 RCPCH guidelines.

The evidence

- 108. As is common in these cases, much reliance is placed upon the history as set out in the extensive medical records, supplemented where appropriate by witness statements from the lead safeguarding doctor and the relevant treating staff.
- 109. In addition to this, the court has been greatly assisted by the overview of this extensive medical history provided by two highly experienced and competent doctors, namely Dr Salvestrini and Dr Ward.
- 110. I heard oral evidence from the following witnesses: Dr H, Consultant Paediatric Surgeon at Hospital B, Dr M, Consultant Paediatrician, Dr MU, Consultant Paediatric Gastroenterologist(Hospital B), Dr Camilla Salvestrini, Consultant Paediatric Gastroenterologist(Court appointed independent expert), Dr C, Consultant Paediatric Gastroenterologist(Hospital B), Dr B, Paediatric Registrar, SD Paediatric Dietician, Dr Kate Ward, Consultant Paediatrician(Independent Court appointed expert.) and the mother.
- 111. I will review the relevant oral evidence given by witnesses insofar as it is relevant to my findings but will not provide a verbatim account of their evidence. Similarly, I have rehearsed earlier in this judgement the key information from the crucial medical witnesses, namely Dr T the author of the safeguarding report, and the report of the two independent experts.
- 112. The reality is that little effective challenge was made to the facts set out and conclusions reached in those statements and reports. There was an overall theme and consistency to what each witness reported.

The Mother's Evidence

- 113. It is undoubtedly the case that the mother found the whole process very difficult and was very emotional when giving evidence. I make full allowance for this when considering her evidence.
- 114. Furthermore she was being asked to recollect significant details from several episodes, some of which happened a number of years before. This is also a factor that I take into account.
- 115. Unfortunately despite making all proper allowances, I did not find the mother an impressive witness. My overall impression was that she had very little insight into the magnitude of the concerns levelled against her and the extent to which her conduct may have caused harm to her son.
- 116. She struggled to shed any real light on her alleged conduct often saying she could not recollect certain things and becoming so emotional that her answers were sometimes hard to follow.

Discussion

- 117. This is a case with a long and complex medical background. A has been the subject of intensive involvement from medical professionals for almost the whole of his life.
- 118. There is no dispute that he suffers from a number of health and developmental challenges. A significant factor in this regard is the diagnosed chromosomal deficiency discussed earlier in the judgement.
- 119. Further, there is no dispute that at about the age of 2 years that he was correctly diagnosed with dysphagia or an unsafe swallow and it was determined that the use of feeding via nasogastric tube was a valid treatment plan, whilst this issue was addressed. Medical opinion expressed at the time was hopeful that this issue could be addressed if medical and dietary advice was followed and that the use of intrusive tube feeding was unlikely to be required in the long run.
- 120. What followed did not justify this early optimism. For several years, A was the subject of prolonged tube feeding and all the complications that came along with this, including exposure to various medical interventions, infections, the broader impairment of his development and ability to lead a more normal existence uninhibited by prolonged stays in hospital and restrictive feeding regimes.
- 121. Nobody underestimates how difficult having an ill child can be and the worries that come with this. This is not a case in which there were no issues. A had established issues with his overall development and there were issues relating to A's ability to feed. Anxiety against such a background is not unusual.
- 122. Unfortunately, the Local Authority case here is that the mother's level of behaviours went far beyond that which is normally encountered and was positively harmful to her son.
- 123. In a response to the schedule of findings filed by the local authority, the mother has made a number of concessions in relation to her behaviour but they were qualified and have been added to during the course of the hearing. By the time of the final submissions the mother made the following concessions:

Concessions

- i. The mother concedes that she overreported/exaggerated the nature and extent of A's vomiting and/or diarrhoea on a number of occasions. The consequence is that A was subjected to unnecessary and at times painful medical procedures and interventions.
- ii. A suffered infections in his gastrostomy site which are likely to have been caused by the mother's failure to adequately clean A's stoma site.

- iii. M accepts that she was at times aggressive and verbally threatening to clinicians treating A. Her conduct at times prevented the doctors from establishing feeding regimes that were considered medically appropriate for A.
- iv. It is accepted that as a result of the above A suffered physical and emotional harm.
- v. The notion that the resiting of A's PEG by Dr C in the summer of last year is the reason for A's improvement is accepted to be erroneous. The mother concedes now that the operation was carried out based on her overreporting/exaggeration of A's symptoms.
- vi. There are the beginnings of the mother recognising that shouting or indeed being aggressive to clinicians in A's presence is likely to have caused him harm (as per the opinion of Dr Ward).
- vii. The dislodgement of tubes/balloons is likely to have been due to suboptimal management/care rather than by deliberate sabotage.
- 124. Thus set against the extensive findings sought by the local authority, the concessions made by the mother have become more extensive but are still somewhat general and it remains necessary for the court to engage with the detail and to make what findings it can.
- 125. Before turning to the specific findings sought by the local authority in relation to the mother's conduct, it is necessary for the court to reach a determination in relation to what an objective analysis of the medical evidence tells us in relation to the accepted diagnosis of the unsafe swallow, what the progress of this presentation was and what it should have justified in terms of treatment and intervention.

The Unsafe Swallow

- 126. I found the evidence of Dr Salvestrini on these issues to be clear and compelling both in her written evidence and in oral evidence which provided further clarity.
- 127. These conclusions were well justified by her analysis of the evidence in the records and from the reports of the treating team and was not shaken in any way by cross examination. She acknowledged that the task of reviewing medical treatment is aided significantly by hindsight and the ability to have an overview of what happened and when and what experience of A's care over time illustrated.
- 128. I quote from her addendum report at E36

"The only robust evidence we have is for A to have unsafe swallow for fluids, not solids. Even during the admission in October 2017 he was eating some food while NGT and gastrostomy fed (F1519 and onwards bundle 20.09.22) The unsafe swallow was diagnosed in July 2017 and he was found to be safe to have thickened fluids by April 2019. During the admission at Hospital A in May 2018, A was eating well, appropriate for age foods despite

receiving substantial amount of enteral nutrition. (F1634- bundle30.9.22). Already at this stage he should have been having only water through the gastrostomy and be challenged to eat the required amount of food for him to thrive. Unfortunately, the reported vomiting has convinced the medical professionals escalate his enteral nutrition. At the very latest he could have been tube free-by the end 2019. At this stage he could have been moved to thickened fluids, reducing gradually the need for tube feeding support. I would have expected for him to take a maximum of six months to(re) learn to drink. A has been fed via tube with supplemental formulas (replacing the need for food intake) despite his ability to eat foods. The nursery meal logs showed that in September 22 he was able to eat and drink age appropriate food textures."

- 129. I accept Dr Salvestrini's analysis of the situation relating to A's diagnosed dysphagia and what was necessary to ensure that he received appropriate nutrition.
- 130. I say straightaway that treatment of these conditions relating to a child's ability to eat, his feeding patterns and his reaction to being given feed, is significantly reliant on the medical staff treating a child being given accurate information by a parent to enable them to make decisions in the best interests of that child. This is especially the case with a child of A's age and level of development, where he is unable himself to communicate the crucial information effectively to the treating team.
- 131. In her oral evidence Dr Salvestrini was keen to stress these points about the difficulties faced by the treating team. She acknowledged that the placement of a gastrostomy Peg in the autumn of 2017 was justified upon the basis of a reported history of the NGT tube being dislodged on 3 or 4 occasions each week, although again in retrospect it was my impression that she was not entirely convinced that she would have taken the same decision.
- 132. She went on, however, to question the wisdom of the progressions of A's treatment from this point onwards, still acknowledging the significant degree of dependence that the doctors had on the provision of an accurate history.
- 133. It is from this point (as summarised at paragraph 18 onwards of the judgement) that A's presenting history started to raise question marks from Dr Salvestrini's point of view. I will turn in a moment to my factual findings in relation to the mother's reporting of various symptoms displayed by A and whether it can be relied upon, acknowledging also the concessions that have very recently been made.
- 134. Once again, I accept the evidence of Dr Salvestrini that by this point the disconnect between what was being reported, the clinical picture and what was being observed by professionals begins to raise concerns.
- 135. At this time, I find the mother was reporting matters which logically were difficult to explain. I give some examples: The fact that A could tolerate NGT feeding but not gastronomy feeding. Both methods deliver food directly to the stomach and thus his ability to tolerate one and not the other was hard to reconcile. The reference to A not passing urine for up to 50 hours, (which I find is an accurate recording of what was being reported), was

- something which was physiologically unlikely if not impossible. Also, the reports of excessive vomiting but the contra indication from the clinical picture that the child was well hydrated and showed no signs of dehydration or kidney impairment.
- 136. Pausing there. It is not said that this child never vomited. Issues are raised in relation to the sheer frequency and extent of what was being reported with little if any clinical justification.
- 137. The further admission in November 2017 following further reports by the mother of gastric feeding intolerance and vomiting, resulted in decisions being taken to undertake an upper endoscopy and laparoscopy, which did not reveal a blockage and confirmed correct placement of the PEG.
- 138. Despite the fact that investigation could not find any mechanical reason for poor gastrostomy feeding, I find that based on the history provided by the mother, the treating doctor, Dr R suspected gastroparesis and thus decided to try feeding which bypassed the stomach and commenced Naso jejunal tube feeding.
- 139. In her evidence, Dr Salvestrini said that at the time of Video fluoroscopy in July 2017 A was able to eat a biscuit and thus could tolerate some solid food orally. Due to the inconsistency between the reported symptoms and the clinical picture which provided little if any reason why this child could not tolerate gastric feeding, by the time of the admissions in October /November 2017, in her opinion, a one to one assessment should have been instigated with a nurse observing what feeds the child could tolerate and then to plan treatment accordingly, armed with this evidence.
- 140. All this should have been done before moving on to jejunal feeding, which Dr Salvestrini opined, was never called for on the facts of this case. The doctor continued that the decision to move to some level of surgical investigation via endoscopy and laparoscopy was not called for since it was clear that the gastrostomy was correctly positioned.
- 141. I accept what the doctor noted from the history, which was at this point the mother was expressing the opinion that whatever problems she perceived A was having, were caused by the gastrostomy. In Dr Salvestrini's words this was "a clear narrative at the time" and it was a narrative that the treating team seem to have followed and again in her view they were "driven away from basics". In her oral evidence, she was of the opinion that from this point onwards the treating teams were acting on reported symptoms. "They kept doing procedures even if the alarm bells were ringing."
- 142. Having considered the evidence in the round including that of the treating doctors, the relevant medical records as well as the independent medical opinion, I find that in late 2017, although A was correctly diagnosed with an unsafe swallow, with the benefit of hindsight, looking at what was objectively validated by testing, the decision to feed him via any method other than NGT feeding was probably not necessary.

143. In reaching this conclusion I do not wish to be seen as being excessively critical of the treating doctors. Their instinct was to trust the parent. It is easy to identify missed opportunities in retrospect. Perhaps the most that can be said is that Dr Salvestrini's appraisal of what signs might have lead to an earlier challenge of veracity of what the mother was saying, may be a useful learning point for future cases of a similar nature. I will address this issue further later in the judgment.

Specific Findings

- 144. The fundamental question for the court is what drove the treatment then and from this point onwards and was the escalation in method and extent of tube feeding and all the procedures and complications that resulted from this based upon accurate history or false and exaggerated claims from the mother and thus largely or wholly unnecessary? To a great extent the mother now acknowledges that she provided false and inflated accounts of the history although she does not provide a full acknowledgement of the matters raised against her by the Local Authority, for example she does not appear to acknowledge that she tampered with A's gastric bag.
- 145. The Local Authority schedule of findings as originally drafted is a thorough and extensive document. Following the conclusion of the evidence, it was decided that a more focused document dealing with the alleged behaviour would be helpful.
- 146. I should say that the Local Authority did not resile from the veracity of the findings sought in the longer document but sought to invite the court to make findings that were representative of the mother's behaviour over time rather that making findings in relation to each and every allegation.
- 147. I refer to the amended threshold findings
 - "The mother has engaged in conduct that has misled medical staff and has resulted in A having many unnecessary medical interventions. Those interventions have included the fixing of gastrostomies and jejunostomies which were not required; the use of parenteral feeding which was not needed; many radiological investigations which should not have taken place; and an artificial feeding regime which could have ended at the latest by mid 2021 and probably much earlier. M's conduct is addressed under three headings:
 - (1) Exaggeration and Fabrication of Symptoms leading to unnecessary treatment including radiation-based assessments and surgery;
 - (2) Anger towards and obstruction of medical professionals seeking to improve N's feeding regime;
 - (3) Culpable failure to prevent infection of A's stoma sites."
- 148. In order to reach my conclusion, I have considered, the relevant oral evidence, references in the medical records and witness statements and expert reports.

- 149. I have also been assisted greatly by the advocates who have prepared this difficult and document heavy case in a thorough and highly capable manner.
- 150. The local authority have presented the case in a comprehensible and realistic manner not seeking to overplay their hand but putting before the court the findings necessary to make a full and well balanced appraisal of A's circumstances.
- 151. Further in considering any specific episodes relied on by the local authority I have asked myself the following questions in reaching my conclusions:
 - i. Was there a medical explanation or diagnosis for what was being reported by the mother?
 - ii. Was there any independent verification to support the facts that the mother reported?
 - iii. Was the child's broader clinical presentation in keeping with what was reported?
 - 152. I have also considered the fact that the mother has accepted, at least to some degree, she has provided false or inaccurate accounts about the A's symptoms. Although this does not prove she has lied or exaggerated on each and every occasion where the local authority alleges she had given an inaccurate history, it is factor that I can place in the balance when assessing issues of her credibility in relation to specific issues.
 - 153. I will now address the specific findings set out by the Local Authority in their revised schedule before reaching my overall conclusions
 - 1. Between September and December 2017 the mother failed to maintain appropriate cleanliness of N's stoma site; she misreported symptoms of feeding intolerance so as to seek a change to his feeding regime; she sought to obstruct gastric feeding when it was medically required.

Medical bundle PDF 453-459; 8085-8094

- 154. I have already discussed the events of September 2017 to December 2017 in paragraphs 127-140 of this judgment when considering the unsafe swallow.
- 155. The mother was taken through the relevant entries in medical records in cross examination. I find that they amply justify the finding sought.
- 156. The entries support that the likely cause for the problems with the gastrostomy site was poor cleanliness and poor site care. It is clear that in the early stages following the gastrostomy placement that nurses saw signs of poor cleanliness and care (see entries 9th and 10th October 2017). I find the mother said she had changed a dressing when she clearly had not and there were examples of the mother not changing A's nappy or adding cream for nappy rash. The mother in cross examination acknowledged to some degree that she probably was not coping well with the overall care of A and I find that this was self evident from the evidence recorded by health professionals around this time.
- 157. The mother when asked about an entry in the records dated 9th November 2017, when the nurses saw a "donut sized granuloma" stated "I was doing my best but I accept there were a

lot of infections." Looking at the evidence of this incident and viewing it in the context of later concerns about site care, I find overall that the recurrent infections were contributed to in large part by the mother's poor care of the site. I find that this issue was a recurrent problem over the following months and years and could and should have been avoided. The cause of this I find was two fold, the fact that the site was not properly cared for by mother on a consistent basis and the fact that gastrostomy feeding was in all probability not required for the duration that it took place, thus opening up the opportunity for ongoing problems.

- 158. I find it is also clear that the mother during this period the mother did misreport symptoms.
- 159. I find the entry for 25th October 2017 is an exaggeration and in part a concoction.
- 160. I find that the notes correctly record that the mother was alleging that this child was "so constipated that he was vomiting faecal matter" just cannot be true. I find that the suggestion that A had not been passing urine for 56 hours, which came from the mother, is also more likely than not untrue.
- 161. The reports of vomiting, which I find were largely exaggerated and over reported contributed to the decision in November 2017 to place the NJT, something which was in all probability unnecessary then or at any time. I accept the opinion of Dr Salvestrini on that matter.
- 162. On 15th December 2017 it is clear from the medical notes that mother appears to provide two contradictory accounts. In a call to the Community Nurse, she refers to A "screaming and throwing up all night "and that he was drawing up his knees and crying out in pain. She also stated A who was this time was being fed by NJT and not via gastrostomy was vomiting milk. In a conversation on the same day, with the Paediatric Day Unit (PDU), the notes record that the mother made no mention about A vomiting or being in discomfort. Her sole concern appeared to be that the NJT had been "pulled". As has been emphasised time and again by all the doctors, feeding via NJT cannot result in vomiting of the type described unless there is an evidenced defect in the gut which there is not in this case. I find that the mother's report about A vomiting milk is false. Once again, the consequence of such false reporting is further confusion in relation to A's medical situation and an escalation of investigations which were either largely unnecessary or wholly unnecessary.
- 163. The mother under cross examination accepted that at this time she found things "too difficult and was not coping".
- 164. Although the mother did appear to accept the inaccuracy of some reporting of symptoms, it could not described as a clear acknowledgment and it did little to shed any clear light on what the mother accepts she did and why she did it.
- 165. I find there is likely to be some truth in the suggestions made to mother by Mr Feehan KC that she was struggling to manage the PEG and this may have motivated some of her actions.

- 2. A was admitted to Hospital A between 10.01.18 and 12.01.18 after she reported that he was vomiting and having diarrhoea multiple times per day. A blue dye test confirmed that the NJT was correctly placed. Significant vomiting and diarrhoea were not witnessed during the admission. Mother overreporting symptoms but reason for that is not fully understood."
- 166. As I have already indicated the mother accepted that she overstated the extent to which A had vomited and had diarrhoea in the context of admission on 10th to 12th January 2018. I accept some vomiting may have been seen but I find that the description of vomiting and having diarrhoea multiple times each day was a significant exaggeration.
- 167. I find that it is telling that once again when A was seen on the ward there was no evidence of vomiting and diarrhoea, he looked well and had gained weight.
- 168. I find that the frequent use of antibiotics may have played some part and caused some diarrhoea but this does not detract from the point about the mother proneness to significant exaggeration.
- 169. The dye test indicated that the NJT was correctly placed.
- 170. There was no evidence of the big vomits the mother reported. In evidence it did seem that she was seeking to suggest that there was some evidence of more extensive vomiting and she stated she wished she had kept the towel to show the staff. I am afraid that I do not accept that such evidence existed, at least it did not show the vomiting to the extent that the mother contended for.
- 171. As was a regular pattern from this point onwards, the symptoms reported at home were not born out by what staff witnessed when A was brought to hospital. The mother states that this action was "not done to deliberately deceive or manipulate but born out of anxiety." Why the mother did this is hard to fully understand, but in the sense that it was a conscious decision to give an inaccurate report of the reality of what had in fact happened, it was clearly deliberate and did deceive the treating medical staff and such inaccurate information had and continued to have real and potentially harmful implications for the treatment provided to this child.
- 172. The situation was made worse by the conduct of the mother during this admission which provided an example of something which unfortunately became a common feature of the mother's interaction with health professionals. On the 11th January 2017 I find the records are accurate when they record this "mum really unhappy, shouting and swearing, saying she wants all the tubes taken out that she is going to complain as this had been over six months and no one is helping and she is going to take A to another hospital." Also on the same date "Very angry, shouting, saying not going to Hospital B and that this is medical negligence."
- 173. I find that that this behaviour combined with the inaccurate reporting of symptoms had a real impact on treatment decisions and often wrongfooted the treating medical team and

- pushed them in directions in terms of treatment and assessment which were on balance not justified.
- 174. Although not contained in the slimmed down schedule of findings, I take the view that some comment and finding needs to be made about the events of February 2018 contained in the original schedule, especially since the mother accepts at least some fabrication of symptoms reported during the admission in late February 2018
- 175. I find that the gastric losses which the mother alleged on the 2nd February 2018 was a false account. The extent of gastric losses was significant. 785 ml over the day, 235 mls over the preceding 3 hours and the child was well and not dehydrated when seen in hospital. Further an abdominal x ray illustrated that the NJ Tube was in the correct position and thus there was no clinical explanation for these losses. This presentation was entirely reliant on the mother's report and was not consistent with the child's presentation from a medical perspective or what was witnessed.
- 176. The mother now admits that reports of vomiting during an admission between 25th and 26th February 2018 was a fabrication. She provided a detailed narrative of A vomiting and placing 2 blankets in the sluice something which she now accepts was not true. Once again, the mother suggests anxiety was her motivation.
- 177. It is hard to fathom how untruthful reporting would ensure that A who she said was poorly would receive the correct treatment, which one assumes would have allayed her anxiety. The concern for the court is that one or two incidents viewed in isolation may allow the court to ascribe a more benign interpretation of the mother's behaviour but, the sheer persistence of the mother's behaviour over the months and years that followed, when many medical professionals attempted to reassure her and sought to allay her fears as to what A's medical diagnosis was and how it should best be dealt with, was routinely dismissed by the mother and the situation made worse by what I find to be her routine misrepresentation and over exaggeration of his symptoms. Further her aggressive and confrontational manner when her view was not accepted made matters worse and effected treatment decisions.
- 178. Although there was a period of time when A was not admitted to hospital, I find that when he was seen at hospital again on 28th November 2018, there was little to support the mother's claims that A was vomiting or draining fluid into his gastric bag to the extent that the mother reported (600 mls fluid) that he was. Once again observation of the child showed he was well and blood testing did not support any suggestion of dehydration which would have been likely if A had the symptoms which the mother alleged. Again, there is no independent evidential support for what the mother reported either. I find that even though some degree of vomiting by A cannot be completely ruled out, I find it is more likely than not that the mother over reported the symptoms once again. I am afraid this is another clear example of the mother exaggerating A's symptoms.
- 3. Between 31.119 27.3.19 A was subject to a hospital admission based on M reporting excessive gastric losses and other symptoms of pain and intolerance of feeding regimes. She was frequently hostile to medical professionals who sought to explain that A could in fact tolerate

those regimes and was obstructive towards staff who sought to implement them until safeguarding procedures were discussed and shared with her.

- 179. I find that there was another largely unnecessary admission to hospital between 31st January 2019 and 27th March 2019 as result of the mother over reporting symptoms of pain, gastric losses and other intolerances to proposed feeding regimes. I find it followed a similar pattern as before namely, symptoms reported by the mother, not witnessed by others and a refusal to accept the reassurance of medical staff that A could in fact tolerate gastric feeding, which I find clinically was the reality. I remind myself that by April 2019 the medical position was that Video fluoroscopy confirmed that A could tolerate thickened fluids. The mother's stance to the proposed feeding regimes was thus objectively unreasonable.
- 180. Looking at specifics as revealed by the medical records and other evidence, I reach the following conclusions.
- 181. It is clear that the mother was reporting gastric losses and milky feeds in the drainage bag on admission on 31/1/19. Once again on balance I find that this is inaccurate report by the mother. A was being fed by jejunal tube on admission and for the reasons already explained this is not possible with jejunal feeding that milk would be found in the drainage bag.
- 182. I find the mother was clearly pursuing a wish to have the PEG removed. At this stage blaming the PEG feed for the problems she reported. Understandably the treating doctors wished to observe A's situation, his ability to feed and his weight and act accordingly.
- 183. There are numerous examples during this admission of the mother being unable to communicate with the treating team in a rational or civil manner. I find the following recordings in the medical records are accurate and illustrate the near impossibility of effective communication and dialogue with the mother on a number of occasions
- 184. 4th February 2019 "I was interrupted multiple times and was unable to finish my explanation"
- 185. 4th February 2019 at 15.35 "Mum became exceedingly angry and demanded care to be transferred". Although the mother subsequently apologised for her behaviour, it did not prevent repeated reoccurrences of the same conduct.
- 186. 17th February 2019 the mother recorded to be "extremely confrontational with the suggestion of NG/PEG dioralyte." Later the same day "Mum became very angry, shouting and raising her voice very loud and aggressive."
- 187. 18th February 2019 "Mum was very aggressive throughout the consultation, stating the gastro team are a disgrace and that we are" killing her son" that she is surprised we have qualifications."

- 188. March 2019 "spoke with mother about her behaviour and how it wasn't acceptable and would not be tolerated. Also was honest and open about our increasing concern and that I'd shared these concerns with the Trust Safeguarding Team. Mother became very abusive towards myself, screaming and swearing. I advised I will not listen to that level of abuse and would discuss further later in the day. The mother later apologised".
- 189. I find the mother's conduct was obstructive to an effective feeding regime being established. I find this was due to a combination of her behaviour and her over exaggeration of A's symptoms of pain and discomfort and him vomiting. I find that on the 8/2/19 the mother effectively blocked A being fed milk when this was not justified. Further, I find that she blocked attempts to feed A through his PEG with water and dioralyte when this was a valid feeding regime proposed by the doctors. I find that the mother also tried to prevent the feeding of dioralyte via the PEG on 15th February 2019 and only agreed with persuasion. This regime was stopped when the mother reported A had vomited, something which on further examination had not been witnessed by members of staff. The mother stated that A had in fact vomited at the entrance to the ward something no one else witnessed. I find this was again in all likelihood a false report.
- 190. The direct result of this was a return to NJT feeding and the insertion of a canula for IV feeding something which was not in reality likely to be necessary if the mother had allowed the treating doctors proceed with their feeding plan.
- 191. Furthermore, by 17th February 2019 it is clear from the notes that it was proving difficult to pass the NJT with three unsuccessful attempts to do so. Despite real concerns about dehydration, the mother continued to be confrontational with medical staff about the use of the PEG feed. Once again, I find the medical notes are accurate when they record this since it is consistent with the mother's approach at this time as evidence by an overall consideration of the records. The mother's actions here put her son at risk since there were real issues about getting nutrition into his body and her obstruction of treatment and her threat to remove A from hospital was in my analysis placing this child at real risk.
- 192. I find that the events noted on 18th February 2019 at 11 am when the mother reported that on trial of the PEG that A "threw and threw and threw " vomit was again an exaggeration. Again, no such thing was witnessed by staff nor was A seen to be in pain as the mother reported.
- 193. I find that the following entry in the medical records on 28th February 2019 effectively summarised the problems that the mother's behaviour was causing to her son. Once again I find the medical record provides an accurate summary of the events:

"discussions surrounding increasing concerns about A's mother. Concerns raised: — swearing, shouting, abusive towards staff members on many different occasions. Reluctance to work with the gastro team. Broken relationships with medical staff making it increasingly difficult to provide accurate care for A. Some over reporting i.e. mother advising A has had an unsettled night, lots of pain when feeding increased, not sleeping due to so much discomfort. Mother's constant objection to increasing milk volumes and requesting A is PN

fed (parental nutrition). Staff on duty overnight reporting A has had a settled night. Due to conflicting information and the mother is at times aggressive behaviour was A is close by and aware of mother's shouting and inappropriate language in ward environment."

The entry goes on to explain that an MDT team would be arranged.

194. The repeated transgressions by the mother in terms of her behaviour make her subsequent apologies ring somewhat hollow.

On 01.09.19 Mother reported that A was vomiting all gastric feed given by gastrostomy. This was not witnessed by the staff. He was given intravenous fluid as a consequence of Mother's exaggerated/fabricated reporting. "

195. I find that inaccurate information was once again provided to the treating team at Hospital A when A was admitted to hospital with a history of vomiting all feeds given by gastrostomy on 1st September 2019. It is important to note that once again these symptoms were not seen in hospital. In fact, A was quickly restarted on gastric feeding which he tolerated. I note that around this time there was evidence that A was eating well at school even if not always consistently and what was more the school was reporting no history of vomiting. These factors cause me to conclude again on balance that the mother's report of the presenting history was unreliable and inaccurate.

On 04.09.20 Mother reported to the Dietitian at Hospital A that A was not eating and he is fed by jejunal feed. He was weighed on 08.09.20, he had gained weight. Mother has exaggerated that A was not eating, A was not receiving enough calories via his jejunal feed to gain weight.

- 196. I agree that the medical records accurately record the conversations that were happening at the time and also what is recorded in relation to A's weight. Dr T said this at para 6.47 of the report:
 - "On 4th September 2020, our Dietician from Hospital A reviewed A's progress. He had gained weight, however she noted that calories received from his enteral feeding plan were below the requirements for growth and therefore he had been eating more than the mother was saying. Mother told the Dietician he was not eating anything. The clinical picture does not fit the presentation."
- 197. There is an irrefutable logic to this statement. The only conclusion that can be drawn from these facts is that the mother exaggerated the report that A was not eating when the reality was that he must have been due to the weight gain recorded.
- 198. Although not included in the slimmed down schedule, I find it is important to consider the admission to hospital in later 2020 and the subsequent transfer to Hospital D for second opinion at the mother's instigation early in 2021

- 199. Whilst at this hospital (Hospital D), it was discovered that A had an intussusception, something that is secondary to a jejunostomy. I find that this may have contributed to some bilious vomiting around this time and I accept Dr Salvestrini's evidence about this.
- 200. It is clear however on the basis of the expert opinion and a review of the medical evidence as a whole that the jejunostomy was never necessary and thus all the procedures, difficulties and complications which flowed from it were entirely avoidable. The mother in the written submissions filed on her behalf now acknowledges this.

<u>Between 22.08.21 and 05.09.21 A was admitted to Hospital A:-</u> <u>Mother reported a history of not tolerating his feeds and vomiting since June 2021, there was minimal vomiting documented during the admission. A presented with an infection in his</u>

minimal vomiting documented during the admission. A presented with an infection in his jejunostomy site which was a result of poor care by M and treated with antibiotics. A presented well on admission, and he was not dehydrated. A received intravenous fluids and antibiotics due to the symptoms reported by Mother. The mother tampered with N's gastric drainage bag to make it seem that there was excessive drainage from his stomach and fabricated reports of milky vomits when fed with such substances."

- 201. The first thing to note is that shortly before this admission in July 2021 following a further VFS, it was proved clinically that A's swallowing problems had resolved with him being shown to be able to swallow thin fluids safely.
- 202. Set against the history and the clinical picture at this time, it must be highly questionable that the mother's history which lead to admission of A to hospital on this occasion was reliable. Again, during admission there was minimal evidence of vomiting and definitely not on the scale reported by the mother. As the records dated 23rd August 2021 "A has not vomited since admission". Once again at this point A was being fed via his jejunal tube and thus any reported vomiting of food passed via his jejunum is hard to credit. Later on 23rd August 2021 the notes record "Mum states there has been a large vomit but this was not seen by staff. Since then A has continued to vomit small mouthfuls of no significant volume." I find the only conclusion that can be reached is that the mother is exaggerating the frequency and extent of A's vomiting.
- 203. I remind myself that once again there was an issue with the gastrostomy site. A had once again been given antibiotics to deal with an apparent infection. Again, in cross examination the mother accepted that she must take responsibility for the recurrent infections due to ineffective site care. I find this may have explained A being a little under the weather but would not explain what the mother was reporting and in broad terms I am not satisfied that there was in reality any real problem with his feeding at this time at all. I note on admission he presented as well and not dehydrated.
- 204. During this admission there were issues reported with the gastric drainage bag containing excessive fluid and also milky vomits. Considering the evidence as whole, taking into account the clear medical evidence that the reported milky vomiting in a child being fed in this way via his jejunum is not logically explicable (there is no evidence the tube was

misplaced), taking into account my previous findings in relation to fabrication, I find it is more likely than not that the mother had tampered with the gastric drainage bag and misreported milky vomits.

Between 06.10.21 and 25.01.22 A was admitted to Hospital B:-

Mother reported that A was in a lot of pain but he was observed to be settled/asleep:-

- i. <u>5am on 31.10.21 (D114 pdf 1840- medical bundle) (C289- main bundle)</u>
- *ii.* 10.30pm on 31.10.21 (D113 1839- medical bundle) G159 Main bundle)
- iii. 4.53pm on 31.10.21 D697 pdf 2423 pdf 2904 (medical bundle) G159 (Main bundle)
- iv. 03.11.21 G160 (Main bundle)
- v. 07.11.21 G161(Main bundle)
- *vi.* 19.11.21 G166 (Main bundle)
- vii. 20.11.21 G166 (Main bundle)
- viii. 23.11.21 G166 (Main bundle)
- ix. 24.01.22 D565 pdf2291 (medical bundle)
- 205. The first thing to note is that despite each of the witnesses filing a statement no effective challenge was made to the content of these statements.
- 206. Considering these examples as well as several others in the medical records as a whole, I find that they illustrate a further example of the mother being liable to over report and over exaggerate A's symptoms and I find the statements and records to be factually accurate. Viewed in the round, they provide compelling evidence to allow the court to reach such a conclusion.

Mother reported that the gastrostomy had not been used for 4 years (G150 main bundle)

207. On balance I conclude that this entry is accurate.

Mother maintained that SALT felt it was unsafe for A to drink fluids (D780 2506 and F2775 pdf 9302- medical bundle)) She refused to be seen by SALT to assess him further (G172- Main bundle, D829 pdf 2555- medical bundle)

208. Having considered the entries I am satisfied that the mother's expressed opinion that A had a chest infection post VFS was the reason why she did not agree to a referral to speech and language to allow further assessment of his ability to swallow fluids. I remind myself that by this point in early 2022 all the evidence was that A could swallow fluids safely as confirmed by the VFS. Indeed, there was evidence from sources that he could eat food orally with no difficulty. I find that once again the mother's approach to this issue was objectively unreasonable. Latterly in the written submissions the mother now appears to acknowledge her stance was unreasonable.

On 18.10.21 Mother resisted the reintroduction of jejunal feeding and A continued to receive fluids and medication intravenously. (D735 2461 – medical bundle).

- 209. Once again, I find the records to be accurate and the mother opposed reasonable medical advice to restart jejunal feeding at that time.
- 25.10.21 Mother refused to allow Dr MU to review A (D606 2332 medical bundle)
- 210. I find that this is more likely than not true.
- On 26.10.21 Mother reported that A had not tolerated his gastric feeds over the weekend, and that he had been screaming in pain, the ward reported that the gastric feeds had been tolerated. Jejunal feeding commenced as a consequence of the reported symptoms. (G157- main bundle, D604 pdf 2330 medical bundle).
- 211. Having considered the medical records and what I have already found to be the mother's proclivity to exaggerate and misreport symptoms, I find that this recording is accurate. In reaching this conclusion I once again take note of the disconnect between what is reported by the mother and what is then witnessed in hospital by the medical staff.
- On 09.11.21 Mother resisted reintroduction of oral fluids despite the VFS in June 21. G161 main bundle F2775 pdf 9301 medical bundle
- 212. Again, I accept this is an accurate recording of the mother's stance on the reintroduction of oral fluids despite the VFS. I remind myself about the matters already discussed in (c) above.
- <u>Between 21.11.21 and 30.11.21 Mother reported that A was not passing urine as frequently as normal and on 1 occasion she said he had not passed urine for 18 hours, the nursing staff reported otherwise G166 Main bundle.</u>
- 213. I accept the unchallenged statement of Nurse E on this point of A not passing urine for 18 hours.
- <u>05.01.22 Mother did</u> not want to follow advice and start a "blended diet" given gastrically (D574 pdf 2300 medical bundle).

Dr S – para 211 G23

<u>Dr T – para 6.80 G41</u>

G164 (main bundle)

214. I accept the evidence that the mother blocked this approach and refused to follow sound medical advice.

On 18.07.22 whilst admitted to Hospital B Mother reported that A does not tolerate PEG feeds but did tolerate oral feeds of variable amounts:-

As a consequence of the reporting the PEG was checked via endoscopy on 20.07.22. (G3 – main bundle). Based on the reported problems he was also given botox to the outlet of his stomach.

215. There is no dispute that the history given by mother was that A could not tolerate PEG feeds.

Due to the severe nature of the reported symptoms, it was felt necessary to proceed with re-siting the gastrostomy further away from the outlet of the stomach (G3 and G9 main bundle). The new PEG was inserted on 10.08.22.

- 216. Dr C gave clear evidence about this issue which I accept. With hindsight it was clear that Dr C very much regretted not questioning the assertions of the mother more forcefully before taking the decision to re-site the PEG. His evidence was clear that what the mother was reporting was not logical in a medical sense and the reported vomiting to the extent she reported was not witnessed or supported by the staff nor were her assertions of the level of pain that A was in. I have no doubt that the decision to re-site the PEG was a further unnecessary procedure driven entirely by the mother over reporting the symptoms A was suffering. The mother now seems to accept this.
- On 11.08.22 Mother reported that A had lots of vomiting, she pointed to a theatre gown and said it was soaked in vomit, upon inspection the gown showed a tiny stain of gastric fluid. She also said that he had had 4 large vomits requiring the bedding to be changed. The large vomits were not witnessed by the nurses and the bedding had not been changed. (F3 and G4 –main bundle).
- 217. Having considered the statement of Dr R, I accept her recording of the events are accurate. Although A may have had a very small stain of gastric fluid on his gown, I find this is yet a further example of the mother's proneness to grossly misrepresent A's presentation. There is no independent witness which provides any support to the mother's claims or indeed any physical evidence either.

On 11.08.22 also reported that A was in lots of pain but A was observed to be comfortable. (G4 – main bundle)

- 218. I accept that the evidence indicated that again the mother's report of the level of pain which A was in was not the same as that witnessed by the treating staff. Although A may have been in some discomfort, it is more likely than not that again the mother's account was overplayed.
- At 8.51am on 12.08.22 Mother reported that A had been very drowsy and screaming in pain, he was observed to be settled and comfortable. (G4 main bundle)
- 219. Again, I prefer the account provided by the nursing staff.

The jejunal tube was confirmed to be in the correct place during an abdominal x-ray. (G5- main bundle)

220. This is a matter of fact and I accept the record is accurate.

On 12.08.22 Mother reported (by photograph) a gastric drainage bag full of milk (F3 main bundle).

221. Set against the history and the findings which the court has already made, I have concluded that the information which purportedly showed that whilst being jejunally fed that A had produced large amount of milk into the gastric drainage bag was again false information provided by the mother. The court accepts the evidence of Dr C supported as it is by Dr T and the independent medical doctors, when he said this "There were multiple photographs of milk in drainage bowls seemingly more than was being put in A's jejunal tube. I said to mum it made no medical sense with the jejunal tube in the correct position and bowel motility being represented as normal that so much milk is draining from the stomach" (G5 Main bundle). The only logical conclusion that the court can reach here is that the history as reported by the mother was untrue.

On 12.08.22 Mother refused to allow A to be fed via his jejunum or PEG because he was vomiting too much and that Dr C "needed to do something else other than feed him in his gut" (F3 and G5 main bundle). Mother was upset, shouting and abusive towards staff in A's presence. He was upset during the incident. (F3 and G5 main bundle)

222. This incident I find once again is accurately recorded in the medical notes and the reports. This episode neatly encapsulates the extreme difficulty which well-meaning and well-motivated professionals had in dealing with the mother over the course of the months and years. Once again there was an inaccurate history being given by the mother. The situation was further exacerbated by the extreme nature of her conduct towards those professionals. On this occasion Dr C was attempting to explain why mother's refusal to allow further attempts at either jejunal feeding or PEG feeding was positively dangerous to A. In his report at G5 in the bundle he continued as follows:

"I pointed out that without us trying but with much closer observations of what A is doing, A would have no way of getting fluid nor nutrition. M was furious, shouting and abusive in her language. This left A in tears. Mum insisted, despite there being no way of safely giving A fluid (and there were concerns about hypoglycaemia) that she was going to take him home if we weren't going to do something different (which could only be intravenous feeding.) We reached impasse where I said I would have to call the police if one tried to take now home as this was not safe."

- 223. I remind myself of the evidence of Dr MU about the dangers connected with IV feeding and the serious problems which this could give rise to in terms of potential infection, sepsis and liver failure. This is another area in which a refusal to accept gastric feeding was possible on the mother's part and her false reporting of broader feeding intolerance, was driving A's treatment in the direction of IV feeding which was positively risky and directly referable to the mother's conduct.
- 224. In final written submissions on behalf of the mother, she correctly characterises her behaviour as disgraceful. It is suggested that this was a low point in her conduct to medical staff. I am afraid I find that this underplays the sheer consistency and persistence of

aggression directed towards the treating medical team over time in circumstances when she did not agree with their approach to A's care. The suggestion is that her anger was driven by worry and concern in relation to A's medical situation. This assertion is particularly ironic since many of the problems have been created for the treatment of A by the mother's failure to provide a clear and accurate history of A's problems over time, the necessary bedrock of any treatment decisions.

225. Once again Dr C's evidence helpfully summarised the realities of the situation. He acknowledged that he had experienced parents exaggerating symptoms before often to get his attention in relation to take seriously some existing complaint which a child had. In the mother's case he said as follows:

"I could not offer her any respite to her concerns. The level of concern expressed by the mother just kept going despite reassurance. This was not normal in my experience. It is the lack of engagement with the explained medical realties."

On 12.08.22 Mother said she was going to take A home, despite there being no safe way of giving him fluids. (F3 and G5 main bundle).

226. I have already addressed this in the preceding paragraph.

On 13.08.22 Mother reported that A "did not look right" and he was in more pain, he was observed by staff to be comfortable (F4)

227. Once again, I accept the accuracy of the information recorded by the nurse.

A tolerated "full feeds into his gut" between 12.08.22 and 15.08.22, with minimal vomiting. He also had some food orally. (G5 Main bundle)

228. I accept this statement of fact gleaned from the records. This presentation is supported by the fact that at this time there was no medical reason why A could not tolerate feeding into his gut. The reality was he could tolerate this method of feeding. This became clearer and clearer following A's supervised admission to hospital in late August 2022 and something which continued to be evidenced when he was in the care of the maternal grandparents. The sad reality is that the common factor which explains the marked difference in A's presentation when in alternative care is the absence of the mother. The mother now accepts in the submission filed on her behalf that the reality is that A "can indeed tolerate gastric feeds and that her levels of concern for whatever reasons were misplaced. She will need assistance to understand her past behaviour."

On 16.08.22 Mother reported large vomits (sick bowls full), he was witnessed to vomit a small amount. (F4 main bundle)

229. I am satisfied on the evidence that this was another exaggeration.

Dislodging of tubes and feeding equipment:

A required 13 radiological procedures to replace the Mick J, this was due to either carelessness in M's care of N, or deliberate or reckless conduct on her part. (Dr S para 349 E29)

230. I am conscious of the need for the court to be aware of the burden of proof and the need to ensure that there is not an unconscious shift of this onto the mother. However, the court is entitled to look at the case in the round and take account of the unanimous views of those medical practitioners who were asked for an opinion about this issue. On any version of events the frequency of the requirement to replace the Mick J was very high in A's case as compared to other patients. As is argued by the Local Authority in the course of the written submissions the court must look at the background to the case and the mother's acknowledged difficulty with managing tube sites. Against the broader history of a willingness to exaggerate and fabricate symptoms, I must confess to being concerned about the possibility of deliberate actions on the part of the mother in connection with the damage to this equipment. That said I must not speculate and only draw proper inferences from the evidence. On balance I am prepared to accept the contention made by the local authority that the mother's frustration and inability to manage the tube feeding and its' associated equipment effectively, is more likely to explain the issues complained of.

Between 2019 and 2020 A's Mick-J balloon burst on several/numerous occasions. There is no plausible explanation for the frequent balloon bursting. Mother has incorrectly manipulated/tampered with/interfered with the balloon. (Dr S para 351 E29)

231. Once again, the experience of the medical professionals was that this was an unusually high number of damaged or burst balloons in the context of the Mick J feeding. Dr Salvestrini commented that the majority of patients do not experience balloons bursting. The most common cause is a yeast infection weakening the structure of the balloon. Another explanation could be the over inflation of the balloon with water. The doctor accepted defects in the balloon could not be ruled out, but it was hard to explain so many balloons bursting. I think the number was 12 or 13. Although once again I have my concerns about deliberate actions set against the broader history, I am inclined to conclude on balance that it was lack of competence on the mother's part allied to some rough handling that is the most likely explanation for the unusually high level of balloon failures.

On 7 December 2017 J's gastrostomy tube was damaged in a manner that did not fit with M's explanation that M had torn it while vomiting; the damage was caused by M deliberately or recklessly pulling the tube. [pdf 454;459;8081-2]

232. It is important to consider the contents of the medical note. "Observation the Monarch tube was protruding from the site. There was about 5 inches of to present with the clamp was about 3 inches from the abdomen and then 2 inches below the clamp the tube stopped – the ended been torn away. When I asked mum how this had happened she said that the force from him vomiting had torn the tube." The note continues "conversation with nurse CCN - both in agreement that it is impossible that the tube could have been torn from the force of vomiting. It is highly unlikely that the tube would tear anyway as it would take incredible force to do

this; and the Monarch is designed to be able to be pulled out manually; so if the tube was caught on something it would not rip or tear."

233. I accept the evidence and the opinion set out in this extract from the notes. In those circumstances it seems very improbable indeed that the mother's explanation could be correct. I find it is more likely that due the problems she was finding with tube feeding that the mother pulled the tube out a fit of frustration. I reject any suggestion that it was caused by A vomiting.

On 04.10.20 A's surgical jejunal tube was found in his bed, despite being taped to his skin; this removal was due to carelessness or recklessness on the part of M (F2898 pdf 9424, medical bundle)

- 234. I find it is more likely than not that again this tube was due to the mother's reckless handling of the tube.
- 235. So those are the detailed findings that I make.

Summary of findings made

- 236. In summary then the findings that I have made boil down to this:
 - I. A was correctly diagnosed with an unsafe swallow in 2017.
 - II. From mid to late 2017 until August 2022, the mother routinely fabricated and exaggerated symptoms of vomiting and feeding intolerance as well as on occasion issues with constipation and passing urine. I find this included tampering with the contents of the gastric drainage bag on more than one occasion and damaging tubes in frustration on occasion.
 - III. The provision by the mother of an inaccurate history combined with her difficult and aggressive interaction with numerous treating medical staff, resulted in A receiving unnecessary treatment and interventions.
 - IV. I find that A's presenting medical condition, did not require anything other than a period of NGT feeding and a gradual transition to normal feeding upon the advice of the relevant professionals.
 - V. I find that NJT feeding was never necessary nor was the insertion of jejunostomy. The mother now broadly accepts this.
 - VI. Thus, I find A was exposed and subjected to numerous unnecessary medical interventions and hospital admissions. These included persisting with the use of gastrostomy resulting in regular infection, the regular use of x-ray to determine whether or not feeding tubes were correctly placed. These were largely unnecessary and exposed A unnecessarily to levels of radiation associated with x-rays. Also the use of IV feeding and the significant potential risks associated with this.
 - VII. The mother's management of the stoma site was the recurrent and primary cause of the infections.
 - VIII. I accept there is no evidence of direct induction of symptoms.

The harm suffered by A which the court finds that he suffered and was likely to suffer as a consequence of the factual findings made.

- 237. The fact finding exercise is not an end itself but a means to an end. The court must consider what the facts mean in terms of the harm suffered. This is the driving force behind the 2021 RCPCH guidelines rather than the main goal being to explain why a parent acted as he or she did. This is matter for further assessment at the welfare stage of this process.
- 238. I agree with the submissions made by the Children' Guardian that it is necessary to look at the harm suffered under the heading suggested in the RCPCH guidelines.

The child's health and experience of healthcare undergoing repeated (unnecessary) medical appointments, examinations, investigations, procedures and treatments which are often experienced by the child as physically and psychologically uncomfortable or distressing; genuine illness may be overlooked; illness may be induced.

Physical Harm & Emotional Harm: Unnecessary procedures, investigations etc.

- 239. I accept the summary provided by the Children' Guardian of what could be classed as unnecessary procedures and investigations:
 - i. 92 radiological investigations between August 2017 and August 2022 [E312 pdf 781]
 - ii. 12 fluoroscopies for MICK-J placements in 1 year [E312 pdf 781] (average is 4x per annum)
 - iii. Numerous re-insertion/replacement of tubes etc
 - iv. Countless blood tests & cannulas
 - v. Multiple courses of anti-biotics, both orally and intravenously
 - vi. The use of a nasal-bridle over a protracted period of time from 2017
 - vii. General anaesthetics
 - viii. Surgeries
 - ix. Lengthy admissions (some for over 3 months October 21 to Jan 22 [G231]
- 240. I also agree with the classification of the feeding regimes as being highly restrictive and highly medicalised and as being unnecessary for A and were likely to have been highly traumatic for him. I remind myself of the earlier findings I made in relation to the evidence of Dr Salvestrini (supported by the other medical experts whose opinion was sought) that nothing more than NGT was ever needed and the reality he has never had any issues with his gut. I remind myself of the evidence of Dr Salvestrini in terms of the harm caused "After June 2021 M refused to allow A thin fluids. Had he had access to oral fluids he would not have needed prolonged tube feeding and therefore all the complications and problems he had around feeding tubes (infections, replacements, dislodgments, surgery, radiology, intussusception. A has been "dramatically" harmed by the resistance to implement fluid intake at the time it was suggested and by the refusal to advice with his feeding plans when advised to" [E35 E504.]

241. Dr C in his evidence made reference to the "number of painful blood tests, let alone surgeries and radiation etc" which he classified as unnecessary including the re-siting of the gastrostomy he himself performed. "Driven by an erroneous history – we end up doing things to this child which are deeply harmful" (Oral evidence of Dr C.)

Neglect: Mother's inability to care for A's medical needs.

242. I have already found that the mother's treatment of the gastrotomy site was inadequate and lead to significant issues. Specifically in terms of harm suffered, once again I agree with the classification of the Children' Guardian:

"The number of infections suffered by A – both in terms of frequency and degree – are out with the clinical experience of the doctors. It is not just the repeated infections that caused him harm – examples of further harm flowing from the infections include;

- i. Painful blood tests;
- ii. Unpleasant side effects of the antibiotics (ie. diarrhoea);
- iii. Impact of regular administration of antibiotics;
- iv. Further hospital admissions due to late identification/treatment of the infections."
- 243. On top of this I find A suffered other pain and suffering due to the mother's neglect, namely as a consequence of what I find to be the management of the site of the nasal bridle witnessed by Dr T in July 2022.

B) Effects on child's development and daily life.

- 244. I find that the impact on A in terms of emotional harm and his broader social, emotional and physical development caused by long periods of unnecessary hospitalisation is obvious. It is hard to predict the long-term impact of such a prolonged experience but I accept it is likely to be profound. The sheer number of admissions to hospital is significant and some of these lasted for months. The consequence of these admissions is enforced separation from his wider family, from friends and from school or nursery. The missed opportunities for social and educational development are clear.
- 245. I can do no better than to quote the oral evidence which Dr Ward gave to the court about the impact of these experiences on A:

"Children find intervention extremely traumatic. In paediatrics, we are used to the fact that children with serious medical conditions inevitably have to go through investigations and treatments and we try to make wards as pleasant as possible with play therapies and clinicians are aware of the importance of being kind and stimulating to children, but you cannot get away from the fact that the ward is a hostile environment. Prevents the child from being at home and experiencing normal social interaction – family, parks etc. Then the child experiencing pain, discomfort, and uncertainty of not knowing when the next painful procedure is to take place. For A this was enhanced by

the fact that he has GDD (Global Developmental Delay) so that his understanding and ability to rationalise what was happening to him was limited. The level of emotional distress was significant for him. Even on the wards, he wasn't able to access a lot of the activities — spent a lot of time in his wheelchair so he wasn't accessing available activities. I would say that for a child to experience the prolonged admissions and amount of investigations that I would see it as significant toxic stress and trauma which we know has an adverse impact on all aspects of development and brain development."

C) Child psychological and health-related well-being.

Emotional Harm: Impact on A of seeing himself as a "sick child"

246. Once again I accept the evidence of Dr Ward about the potential harm that can be caused by a child in A's situation perceiving himself as a "sick child":

"It causes confusion. Children are very adaptable but the real risk of a child perceiving themselves as more disabled than they are, it effects self-esteem and confidence and will affect the child's whole life. The child will accept it and not know any different so will continue to behave as a disabled person."

Emotional Harm: Impact of Mother's behaviour on A.

247. I have already summarised in detail in my findings the numerous occasions on which I found that the mother had behaved in a difficult, aggressive and obstructive manner to professionals often in the presence and earshot of A. Again Dr Ward was asked about potential impact in her professional view as a paediatrician and she said this in her oral evidence:

"will have added to the stress and trauma. We know from research that children who live in an environment where there is conflict and anger, will develop emotional difficulties and it may impact on behaviour. They may have an exaggerated fight or flight reaction and it may well impact on their own behaviour and lead them to over-activity, episodes of dysregulation and problems in a small setting where they may find it difficult when they are distracted by small stimuli."

- 248. Both Dr T and Dr C gave first hand accounts of A witnessing this behaviour. Dr C said this in relation to the admission in August 2022 "When the shouting starts and when the swearing starts, he knows what is going on and it is bad. I think he doesn't understand why it comes out of the blue like it did and he was clearly distressed."
- 249. I have no doubt that the mother's behaviour which was repeated on several occasions across several admissions and in different settings resulted in A suffering emotional harm. I find that the connection to medical setting has real potential cause him be over sensitized and stressed by future contacts with medical professionals as a consequence.

Change in A's presentation since August/September 2022

- 250. A further necessary exercise in assessing the harm suffered by A that is attributable to parental care is to consider what has happened since. I have already touched on this in the findings I have made when considering the Local Authority schedule in relation to the events of August 2022.
- 251. As is submitted on behalf of the Children's Guardian, the contrasting comparison of "before and after" when considering what happened when A was in the care of the mother and with the situation when he subsequently moved to hospital and then to grandparental care, is striking. I refer to the matters listed in the written submissions prepared on the behalf of the Children's Guardian which I find accurately reflect the areas of improvement:

SD, in her oral evidence, summarised the improvements as follows;

- i. Ceasing of jejunal feeding;
- ii. Tolerating gastric feeds
- iii. Only receiving 37.5% of his nutrition through his gastrostomy
- iv. But for a viral illness in February 2023, he has steadily gained weight
- v. Ability to take PediaSure shakes orally
- vi. Volume of food eaten orally has increased.

In addition to the above, the following improvements have also been noted:

- i. Only 1 infection in 6 months compared to numerous infections on M's care (per the updating statement of Dr T [SB C23])
- ii. His use of hearing aids is more consistent and his speech has improved.
- iii. He is no longer using his wheelchair. [A9 pdf 14] [SB pdf 30]
- iv. There has been improvement in toilet training. [A9 pdf 14]
- 252. As I have already found the only logical explanation for this is the change in carer. As before, I find Dr Ward hits the nail on the head:

"his early unsafe swallow was not a permanent problem and was capable of improvement. Not only his current improvement but the VFS to support that. From that evidence I think we can assume and predict that he would have been capable of improving to this level more quickly and without the interventions that he had and that the perplexing presentation seems to have been resolved by a change of carer, not by any medical intervention."

- 253. In conclusion I am satisfied that the harm caused to A which I have clearly identified is attributable to the care of the mother.
- 254. I accept that the mother is still a relatively young mother. I also accept that prior to the court receiving further assessments at the welfare stage, there is no evidence of similar concerns relating to B and C, although the current findings must cause some concern about what the impact of all this has been upon them.

- 255. I further accept that it does seem to be the case that the mother has not set out "deliberately" to harm A and that her actions have been "set off" by A having some medical issues.
- 256. As I have stated I find that she not only exaggerated A's circumstances to a significant degree over a prolonged period on occasions this moved into fabrication and wilful misreporting of symptoms as well.
- 257. There is no doubt that this shaped the course of A's treatment dramatically.
- 258. Thus I find that in the context of the RCPCH the impact of the mother's action have been profound and although they do not amount to induction of illness, the sheer persistence of her conduct and unwillingness to accept any form of reassurance from the doctors and press on with reporting symptoms that were both inaccurate and on other occasions patently false is serious. I have detailed the impact it has had on A in terms of harm.
- 259. It is positive that there is now some acknowledgement by her of her behaviour both in earlier response documents, the final submissions filed on her behalf and to a lesser extent in her oral evidence.
- 260. However, as I determined in my general comments about my observations of her evidence earlier in this judgment, I remain concerned that she does not appear to show anything approaching full acceptance of the harm she has caused or indeed any real insight into what has happened or why.
- 261. These are matters which must await further assessment and also further reaction from the mother having had time to digest the court's findings.

The role of F

- 262. At an early stage of the fact finding hearing the Local Authority took the view that the evidence did not allow any findings of failure to protect to be made against F. On behalf of F, Mr Donnelly made a number of forceful points about his client's overall involvement and his responsibility for the current state of affairs.
- 263. In short, it is argued that the mother took on responsibility for the medical care of A alone and had all contact both direct and indirect with medical professionals. Mr Donnelly also makes the point, which is a fair one, that if medical professionals are not being criticised for accepting what the mother said at face value and trusting her reporting, then why should he be treated differently? Further if they should not be criticised with hindsight then why should he be so criticised?
- 264. In broad terms I accept Mr Donnelly's submissions. At the next stage however, it will be necessary to assess F's role in the household and examine what he says in the course of assessment about his role in these events and within the family. The court has yet to determine

the ultimate welfare outcome for the children but his role could well be a pivotal one in the context of any suggestion that a plan of rehabilitation should be pursued for M and F as a couple insofar as A is concerned and also if the plan is for the other children to remain in the joint care of the mother and F. His reaction to this judgment will also be important.

Criticism of the treating clinicians

- 265. At an early stage in the process this matter was raised as a potential issue. Subsequently no party, with my approval, sought to pursue any criticism on the basis of the evidence as it was then understood to be.
- 266. Following the conclusion of the evidence I do not think there are any grounds upon which I should take a different view.
- 267. In broad terms, for reasons I will now explain, I do not think this is a case in which significant criticism of the treating clinicians could be justifiably made. It may be that certain decisions with the benefit of hindsight may have been different but that is another matter. This case may give rise to an opportunity for learning from experiences which professionals have had in the context of A's treatment and care and future improvement as opposed to criticism of past conduct.
- 268. Dr Ward summarised the basic principles which underpins the work of paediatricians when she said this in her evidence:

"We depend on what we are being told by parents and it is our nature to accept that the parents are the expert in their child and it takes a shift for professionals to disbelieve something that has been stated."

269. Dr Ward continued to explain the dilemma facing doctors in cases such as this:

"Two points are relevant — one has to be clear that the guidance is new. It only came out in Feb 2021 in fairness to the clinicians. If you turn the clock back, one of the difficulties with fabricated illness where it is not like induced illness where you can do a test and see that the child has been given a substance. This is much more subtle and difficult. We depend on what we are being told by parents and it is our nature to accept that the parents are the expert in their child and it takes a shift for professionals to disbelieve something that has been stated. I am yet to come across a case where I haven't thought 'if only' and I'm sure the clinicians have thought 'if only', but there is a certain amount of gathering of evidence that was necessary. One could argue that with hindsight it wasn't necessary. Looking at the notes, nursing staff had suspicions early on. The guidelines are not helpful in getting the collaborative opinion of health professionals. Whether it would have speeded up the outcome for A or prevented some of those interventions is difficult to say. One would like to think that it would but when one is dealing with subtleties — I've spent a lot of time going through the chronology and I had the benefit of hindsight. It is much more difficult as a clinician when you are working with a child and there is another hospital involved with the

- child as well. The practicalities are quite difficult. As we begin to understand the nature of this problem, we will be able to engage parents in a more meaningful way."
- 270. It was clear that Dr Salvestrini was of the opinion that a different approach could have been taken in late 2017 in terms of observing A's ability to feed at that point under the supervision of a designated nurse and also made some comment about the decision to move to jejunal feeding.
- 271. Dr Salvestrini was keen to stress however that much of the treatment was driven by what now is shown to be a false or exaggerated history and she was quick to say that she had the benefit of hindsight. She emphasised that the approach taken is that parents know best and that doctors "really do need to be pushed to the limit to see that there is no clinical explanation." When asked if it was a conclusion that doctors are naturally slow to reach that a parent is being untruthful, she continued "Yes. Even harder when you have a child who has a diagnosis and clinical conditions. It is harder. It is easier to find a medical justification than stopping, reflecting. The system doesn't allow you to stop and take time we are under pressure to treat and discharge patients and send them home. "
- 272. This echoed the evidence of Dr C who said this "There is a moment of trepidation when my job moves from trusting a parent to wanting to triangulate and verify what a parent is telling me. That moment came on 10.8.22."
- 273. It was clear to me that Dr C was critical of himself for being pressured into undertaking a procedure to re-site the gastrostomy in August 2022 which, with hindsight, was not needed. If I may say, I think he was unnecessarily critical of himself but it does serve to illustrate that often the fiercest critic of an individual professional is that professional themself.
- 274. All in all, I have concluded that in retrospect there were missed opportunities to question the history being given by the mother and thus to potentially put a brake on the speed and trajectory of the interventions subsequently undertaken in relation to A's treatment.
- 275. That said I find it is not fair or appropriate to raise direct criticism but rather to encourage the treating team to review the history and learn from it.
- 276. The reality here is that all of the professionals were committed and devoted to doing their best for A and trusted what they were told in the context of their care of a child who did have a diagnosed medical issue. The overwhelming cause of the unnecessary treatment interventions which A were received was the conduct of the mother.
 - 277. Those are the findings of the court.