



Neutral Citation Number: [2021] EWCOP 69

Case No: 12975950

**COURT OF PROTECTION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 13/12/2021

**Before :**

**THE HONORABLE MR JUSTICE HAYDEN**

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**Between :**

**A NHS TRUST**

**Applicant**

**- and -**

**(1) G (BY HER LITIGATION FRIEND, THE  
OFFICIAL SOLICITOR)**

**Respondents**

**(2) LF**

**(3) M CCG**

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**Michael Mylonas QC** (instructed by **Hill Dickinson LLP**) for the **Applicant**  
**Sophia Roper** (instructed by **the Official Solicitor**) for the **First Respondent**  
**John McKendrick QC** (instructed by **Irwin Mitchell LLP**) for the **Second Respondent**  
**Debra Powell QC** (instructed by **Hill Dickinson LLP**) for the **Third Respondent**

Hearing dates: 6 -13 December 2021  
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**Approved Judgment**

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MR JUSTICE HAYDEN

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 incapacitated person 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.

**Mr Justice Hayden:**

1. I'm concerned with G who is approaching 27 years of age. I've heard evidence over the course of five days with submissions this morning and I am delivering this judgment, ex tempore, because it is important to the parties to know my decision and the reasons underpinning it, in order that plans can be put in place for G's future in a timescale which accommodates her needs.
2. There were difficulties at G's birth. She was born in a generally poor condition. It became obvious to medical staff and her parents early on that she was failing to meet significant developmental milestones. It is important to identify that she was able to smile, at around 3 months, able to sit, with some support, at about 8 months and was crawling at 1 year. Later, with support, although by this stage conspicuously delayed, she was able to stand, although she was described as 'wobbly'. None of these challenges eclipsed her sunny personality. She was a happy little girl from the start of her life and her happiness was manifestly infectious to those who came within her orbit. Her parents have taken great delight in her throughout the whole of her life and continue to do so.
3. What was noted, early on, was that her comprehension of the world around her was notably more advanced than her limited and restricted motor development might otherwise have indicated. I have emphasised this disparity between her comprehension and developmental impairment because it may, potentially, cast some light on understanding her present level of awareness. Her parents believe G to have a far greater perception and understanding of the world around her than do her doctors.
4. As G developed it was clear that she had difficulty feeding. This was said to be related to a nasopharyngeal incoordination. Though efforts were made to resolve it, they were ultimately unsuccessful. In August 1997, when she was around 2½ years of age, a gastrostomy feeding tube was inserted. G was also diagnosed with long-sightedness. Her eyes showed an evolving retinopathy (an abnormal appearance at the back of the eye when viewed through an ophthalmoscope). From having a normal retina at approximately 1 year of age with dull macular reflexes, she developed extensive chorioretinal mottling, attenuated retinal vasculature and slightly pale optic discs, (where the optic nerve enters the back of the eye). There was, therefore, a marked deterioration.
5. By her 6th birthday G's treating consultant paediatric neurologist had documented what is described to be a 'plateau in her development' in the preceding year, most notably in motor skills and expressive communication. Her parents had also reported her speech to be less intelligible and it was noted that though she had enjoyed exploring by crawling hitherto, that had become less extensive.

6. As well as significant ataxia, a generalised disorder of coordination, balance, and speech, G had also developed a tremor and a tendency to undershoot or overshoot when trying to reach for an object, in a way that had not been present before. Her head circumference was by this time below the 3rd centile, though it had been around the 50th centile when she was just under 18 months old. It illustrated an evolving microcephaly.
7. Scans were undertaken and brain imaging was conducted. In November 2000 scans confirmed that white matter myelination was arrested at a very primitive stage with no significant change in the preceding 4 years. The myelination is the development of sheaths that surround the nerves.
8. G's medical records and the conclusions of the various tests I've referred to were reviewed by Professor Olof Flodmark at the department of neuro-radiology in Carolinska Hospital, Stockholm, Sweden. Professor Flodmark has brought a wider non UK perspective to bear in a significant number of cases and is a highly respected neuroradiologist. He concluded, in conjunction with his clinical colleagues, that the maturation process of G's brain had been "*severely delayed*". He observed as follows:

*"In fact there appears to be very little advance made since the stage of maturation usually recognised at term. The white matter is not myelinated due to severely delayed myelination rather than dys- or demyelination. The cause for the delayed development is unclear and the pattern is in my experience non-specific. Had this patient been a male, I would have suggested Pelizaeus Merzbacher Disease as the most likely diagnosis."*
9. Professor Flodmark's diagnosis has been the subject of some debate between the parents and the treating clinicians. It is entirely unnecessary for me to resolve any difference of opinion. It is a label which casts no light, in my view, on G's present needs or her likely future needs. As I understand the parties' positions nobody would disagree with this analysis at this point in G's life.
10. In April 2008, by this time 13 years of age, G was admitted to a local Hospital. She had at that stage a significant chest infection, but while she was being positioned, in order that an x-ray could be undertaken, she sustained a fractured right femur. Her clinical condition deteriorated with increased secretions, to a degree that eventually required mechanical ventilation. G was transferred to A NHS Trust's Paediatric Intensive Care Unit (PICU). It was there, tragically, on this admission, that the Trust's team confirmed a diagnosis of osteosarcoma in the right leg. G underwent a significant amputation of the leg up to her hip. In the course of that investigation, she was identified as suffering from osteopenia, which is an indicator of low-density bone mineral. That was accompanied by osteoporosis. The extent of the fragility of her bone structure was confirmed when she suffered an entirely spontaneous fracture of her left femur in 2009, by then aged 14 years.
11. It is important to include in this chronology of her painful medical deterioration, the striking fact that throughout it all, G maintained the cheery, smiley personality which was noted from her earliest days.

12. In 2008 the Multi-Disciplinary Team (MDT) noted, at a meeting held in August, the following:

*“G demonstrated early onset of movement disturbance and weakness of the limbs with absence of tendon reflexes. She clearly had a disorder affecting the central nervous system. Initially the cause of [G’s] neurological problem was unclear but as time went by G’s signs and symptoms were very suggestive of Pelizaeus-Merzbacher Disease, (PMD). This is a rare condition that tends to affect boys, being sex-linked, but has rarely been reported in girls. The progress of G’s neurological condition over the last several years fitted extremely well with the diagnosis of PMD. In addition, recent MRI scans were also fully compatible with this condition. G has undergone genetic testing for this condition both in the past and more recently to look for mutations in a number of genes associated with PMD. None of these mutations were found. Nevertheless, Dr Appleton feels that, as above, G most likely has this PMD. In addition, Dr Appleton has discussed G’s case with experts in a countrywide forum and those neurologists that replied also stated that G’s condition fitted with PMD. There seems to be no obvious alternative diagnosis.”*

13. As I have said, and in the hope of reducing conflict, I do not consider the PMD label to be relevant. What is clear is that there was an onset of movement disturbance and that this established beyond any doubt that G was suffering from a progressive disorder affecting the central nervous system.
14. Dr A went on to explain that PMD is a progressive condition for which there is no treatment or cure. Whatever the diagnosis, it is now clear that G has a condition which has not been receptive to treatment or amenable to cure. Though her parents are resolved to preserve and extend their daughter’s life, they broadly accept the reality of her condition. They do not need to be told that her illness is progressive, they have seen it for themselves in their devoted day-to-day care for her.
15. It is the singularly most alarming feature of this case that although G was admitted to the Trust’s Hospital when she was 13, for which she was fortunate, she remains there today, now approaching her 27th birthday. The reality therefore is that G has been in the Hospital for the entirety of her adult life as well as a significant part of her childhood. This is an entirely unprecedented situation for the nurses, doctors and indeed for the lawyers. G is not a child, she is an adult with serious progressive disabilities.
16. The Hospital is no longer an appropriate place for G, a 27-year-old woman. I agree with Miss Debra Powell QC, acting on behalf of the Clinical Commissioning Group (CCG), that at some point, G’s continued placement there became irreconcilable with her dignity. I would go further, in these circumstances where the parameters of her personal autonomy are circumscribed by her condition, the continued placement at the Hospital limits, unnecessarily, the small sphere of autonomy that remains available to her i.e., to be treated as the young woman she now is and not as the child she was upon admission. It is important to record that nobody, including G’s parents, has suggested that the Hospital is now the right place for her. In my judgement it is axiomatic that this

children's hospital, however great its resources and skills, is ill-equipped to meet the emotional, medical and physical needs of this young woman.

17. In this challenging and poignant case, it is important, as Mr Michael Mylonas QC, acting on behalf of the Trust, has emphasised, both in his opening and closing submissions, to identify the significant areas of agreement between the parties. This is a constructive approach and one which ought to illuminate future consensus. Because it is the starting point in planning for G's future it is important to emphasise, even at risk of repetition, that all agree that G's needs are not being met to the degree they require to be at the Hospital. Further, whilst nobody can be sure how long G may live, all accept that time is not on her side.
18. The parents have for some time now consistently expressed the view that they wish G to return to live with them at their home. I had, like counsel, used the word 'return' on a number of occasions, but that tends to occlude the reality of the fact that she has spent her entire adult life in the hospital.
19. In 2013, there were strong efforts made to facilitate the parents' wishes to have G returned to their care at home. As I understand it, the plan progressed to the extent that modifications were made to their property and there was an arrangement that the local hospital, which had significant experience of G's condition, would oversee her care via the intensive care unit. That hospital was easily accessible to the parents' home.
20. Ultimately, the discharge did not take place because the father (LF), in particular, was highly agitated and anxious concerning the availability of the support services close to the family home, properly to care for G on her discharge. It has not been necessary, nor would it have been proportionate, to investigate the substance of LF's anxieties in 2013. I have no doubt that they were genuinely held and that they were rooted in his love and concern for his daughter. Moreover, I by no means discount that there may have been some substance and legitimacy to F's concerns.
21. The progress of the litigation before me has already occupied greater court time and moved at a slower pace than I would otherwise have anticipated or ordinarily have countenanced. The Mental Capacity Act 2005 (MCA) does not contain within it a principle highlighting the imperative of avoidance of delay, which has now and for some time been a significant feature of most areas of the common law. Though it is not drafted into the framework of the MCA, the avoidance of delay principle ought to be regarded as a facet of the protected party's Article 6 and Article 8 rights. Delay in proceedings in the Court of Protection should ordinarily be regarded as inimical to the welfare of a protected party.
22. This application initially came by way of a s.21A challenge to the standard deprivation of liberty authorisation (DOLS) granted by a local City Council. It was generated on LF's application. On 18th October 2017, before Roberts J, it was agreed that the real issue related to G's 'best interests' concerning both her residence and care and in particular whether she could leave hospital to live in the community. Thus refined, it was essentially the same issue that had arisen in 2013 which foundered for the reasons that I have set out.
23. In a detailed order, Roberts J required that the proceedings continue as a "best interests" application and directed that the NHS Trust should be substituted as the applicant. The

Official Solicitor accepted the court's invitation and was appointed as G's litigation friend. LF had previously occupied that role but was joined as a respondent. G's mother was not joined as a party, though I have effectively regarded her as such during the course of this hearing.

24. On 4th February 2018, Dr Harriss, a Consultant in rehabilitative medicine, provided an independent report. On 7th February 2018, the case came for the first time before me as a paper application following an advocates' meeting the preceding day. There was uncertainty both as to the possible location of G's destination on discharge and as to the public bodies that would be responsible for funding her accommodation and her care. I made orders to resolve those issues which I need not further burden this judgment with.
25. On 20th April 2018, the case came back before me. There had been difficulties identifying an appropriate expert to provide a report and I gave permission to the Official Solicitor to disclose the papers to and seek an opinion from Dr Andrew Bentley, a Consultant in Intensive Care and Respiratory medicine. He prepared a report, dated 12<sup>th</sup> August 2018. He also provided a supplemental, later report. Additionally, he has given evidence before me.
26. In December 2020, the CCG was joined as a party to the proceedings, by which time it was clear that they would be the public body responsible for funding. It was also agreed that discharge to the family home was no longer being considered as a viable option. For the avoidance of any ambiguity the parents remained resistant, to a placement near their home. The Trust also considered it to be an unsuitable option.
27. In order to advance an alternative plan, the parents identified and took out a lease on a 2-bedroom bungalow, reasonably close to the Hospital, in or around June 2021. That property, I am satisfied, remains available to them. There was some issue as to whether the lease had expired, but LF has persuaded me that it has not.
28. Both the Trust and the CCG have identified an alternative option, namely a residential unit known as 'A Home'. Costings were obtained and have been placed in evidence before me. On the 29th November 2021, just a few weeks ago, the CCG purported to take what is described now as a 'preliminary decision' not to fund a package of care in the rented bungalow. There was at the beginning of this hearing a great deal of discussion as to the impact of that decision on the scope and ambit of these proceedings. I was reminded that it was open to the family to make a further application to the CCG if they were able to establish 'exceptional circumstances'.
29. Recognising the parents' long-standing ambition for G to return to their care, I did not permit the CCG's 'preliminary decision' on the question of funding to excise from my consideration an evaluation of the parents' proposals i.e., for G to live in the bungalow with them. I emphasise that I have approached my assessment on the basis of identifying G's best interests, deferring the question of finance until that became clear. That said, I have in mind of the decision of the Supreme Court in: **N v ACCG and others [2017] UKSC 22**. That judgment emphasised that the Court of Protection:

*"has no greater power to oblige others to do what is best than P would have himself. This must mean that just like P the court*

*can only choose between the ‘available options’.*” per Lady Hale, §35

30. In her judgment, referring to the earlier decision of the House of Lords in: **Holmes-Moorhouse v Richmond upon Thames London Borough Council [2009] UKHL 7; [2009] 1 WLR 413**, Lady Hale explained at §36 that:

*“The authority was entitled to take into account the fact that housing was a scarce resource, the claims of other applicants and the scale of its responsibilities, when deciding the issue of reasonableness for this purpose. Nor should a family court use its own powers as a way of putting pressure upon the local authority to decide in a particular way.”*

31. Those strictures apply with every bit as much rigour to the Court of Protection. But it is important, as Mr McKendrick QC urges on behalf of the parents, not to conflate ‘pressure’ from the Court with the obligation on the court properly to survey the wide canvas of P’s welfare interests.

32. At paragraph 37 of **N v ACCG and others** (supra), Lady Hale reiterated that public authorities, including the NHS, have their own schemes, processes, principles and criteria for assessing the needs of and deciding what services they may be able to provide for those in respect of whom they have statutory responsibilities. These decisions can be challenged on conventional judicial review principles. In addressing whether the Judge, at first instance, in the Court of Protection had been right not to entertain a challenge to a public funding decision, Lady Hale observed at paragraph 14:

*“Judicial review was the only proper vehicle through which to challenge unreasonable or irrational decisions made by care providers and other public authorities. In rare cases where a public authority might be acting in breach of convention rights by refusing to fund a particular form of care that could be raised in the Court of Protection by way of a formal application under section 7 of the Human Rights Act 1998. In this case, as contact at the family home was not an available option now or in the foreseeable future, the court should not embark upon a best interests analysis of contact at the parents’ house as a hypothetical possibility. Hence she was satisfied that the contact plan now proposed by the CCG was in MN’s best interests. She therefore made a comprehensive order, among other things, declaring (1) that it was in MN’s best interests to continue to reside and receive care at his current care home or, should that come to an end for any reason or the CCG or public body responsible for his residence and care decide that it is no longer in his interests, to move to and reside and receive care at a placement identified by them; and (2) that it was in MN’s best interests to have contact with his parents and other members of his family in accordance with the detailed plan set out in a schedule”*

33. Miss Powell submits that there would be no useful or proper purpose in the Court seeking to determine, at this stage, how much nursing care would be required as part of a domiciliary care package. Such an approach, she submits, would be to intervene in the CCG's decision-making process in the exercise of its public law functions, which is not the role of the Court of Protection. The CCG's own processes allow for discussion and consideration of the points of challenge that G's parents wish to raise in respect of the way in which the CCG has assessed and costed the proposed domiciliary care package thus far. G's parents have not yet had an opportunity fully to consider or articulate their concerns. A statement, prepared by the director of 'Acute Need', a domiciliary care home facility was served shortly before trial on behalf of LF. This sets out further detail concerning the proposed domiciliary care package required to support a placement in the bungalow. These issues, Miss Powell suggests are best addressed in fully informed round table discussions between the relevant people rather than in cross-examination in court.
34. Miss Powell further argues that a determination of this issue by the Court would not materially affect the timing of the CCG's ultimate decision on whether it would be prepared to fund a domiciliary care package; even excluding on-site nursing care entirely, the cost of the domiciliary care package has been assessed by Acute Need in the recent witness statement at £9,303.84 per week [§10] (£483,799/yr). The cost of A Home is £6,082.56 per week [523/D402] (£316,293/yr). Even if the court were to determine that no on-site nursing care at all would be required on an ongoing basis, the cost of the domiciliary care package would still be some 53% higher than the cost of A Home. On this basis, Miss Powell submits and I agree, that whether the CCG decided that it would or would not be prepared in principle to fund a domiciliary care package, a further hearing to determine where it is in G's best interests to live would be required in any event.
35. Plainly there is an argument based on the case law above, that I should not have permitted the parents' team to argue that it was in G's best interest to return home on a domiciliary package, given that the CCG was unprepared to fund it. I have been uncomfortable throughout with the labelling of the parents' proposal as 'the hypothetical care plan'. As all parties agree, properly analysed, the distinction between the two emergent positions has become refined. There are two opposing analyses. The parents consider that G, with appropriate support, could return to their care in a few months' time. The clinicians argue that a direct move home, after so many years in hospital would, in effect, be setting G up to fail, creating the real and not fanciful prospect of a breakdown of placement which they, correctly in my view, identify as the worst possible outcome. The proposal for A Home is identified as a bridging placement from which, if all goes well, it may be possible to look at a reunification of this family.
36. Thus, we are not, dealing with a purely hypothetical possibility, we are considering an agreed objective (i.e., reunification of the family), where the issues in dispute revolve around the need for further assessment, support, training and timescales. This is a proper and legitimate enquiry for this Court and an entirely different forensic scenario to that being considered by Lady Hale in **N v ACCG and others**. A Section 7 Human Rights Act application may be made both formally, as Lady Hale indicates in the passage quoted above (see para. 32) but it can also be made on the Court's own motion. The positive obligation to respect family life in the sphere of adult care (which is what we are concerned with here) is reflected in a wealth of domestic and European



statements of principle. It finds full and clear expression in the decision of Munby J (as he then was) in **Re S (Adult patient) (Inherent Jurisdiction: Family life) [2002] EWHC 2278** (Fam):

*“115. The Official Solicitor has made clear in his witness statement that he accepts and supports Mr F’s recommendations as to where S should live. His reasoning is in substance the same as the local authority’s. Summarised on his behalf by Ms Cains, his case is that it is not in S’s best interests to live any longer with DS because of:”*

*i) instances from time to time when the level of pressure on DS has provoked unacceptable behaviour by him towards his son;*

*ii) evidence that DS has used his son as a lever in pursuing disagreements with statutory authorities;*

*iii) substantial evidence of ongoing difficulties and disputes about respite care arrangements; and the likelihood that disputes about respite care, care arrangements, the provision of services and concerns about incidents in respite care would continue due to DS’s inability to change and his rigid concepts, belief systems, thinking and behaviour - these factors, and the likelihood of S being used from time to time as a lever, would be likely to impact on his emotional wellbeing and compromise the level of care provided for him.*

*116. I agree with the local authority and the Official Solicitor. Insofar as their case is based on assertions of fact there is, I am quite satisfied, a mass of evidence - much but by no means all of which I have already mentioned - to support each and every one of their assertions. Insofar as their case is based on an evaluation of the present and concerns for the future, I agree with that evaluation and understand and fully share their concerns.*

*117. I do not doubt that DS has been motivated throughout by his love of and concern for S. I do not doubt that DS has striven to do what he believes is best for S. His devotion for S now and for so many years is palpable. It demands recognition and humble admiration. But the sad fact is that DS has buckled under the strain. That is not a criticism - many would have buckled long ago. Some of the time he can cope, but he cannot always cope. In the past, perhaps, he was able to cope for much of the time. But the evidence indicates that in recent years he has found it more, and more frequently, difficult to cope. These difficulties will, I believe, increase in future.*

37. I should record that though some of the witnesses have given their evidence by way of video conferencing platform, most of the evidence has been given in the court room from the witness box. It is perhaps important to signal that this was the strong preference of the parents, but I sensed that, in this case, it was shared, with equal enthusiasm by the treating clinical team. The lead clinician, Dr B, Consultant Paediatrician, has been in the court room throughout, including for submissions and judgment.
38. It is a feature of this case that everybody involved in it at whatever stage has commented that these parents are passionately supportive of their daughter, determined to identify her best interests and committed to fight for them with every fibre of their being. Equally, this is a hospital which is suffused with a philosophy which places the care for the patient at the centre of the process in a way which is woven into every aspect of its day-to-day approach to treatment. The Hospital provides an environment which strives for and achieves professional excellence. It requires to be said that the parents have regularly paid fulsome tribute to the care that their daughter has received and have been, most particularly in LF's case, incorporated in to the daily medical regimen.
39. As foreshadowed above, the issues at the beginning of the hearing were clearly identified. During the course of the evidence LF, in the witness box, recognised explicitly and for the first time that it was no longer in G's best interests for her to receive cardiopulmonary resuscitation ("CPR"), in the event of cardiac arrest. It has been clearly asserted by all the clinical team that the administration of CPR is likely to cause significant distress, fractures and is, in any event without identifiable benefit. It is important to emphasise that this has been the position for at least two years.
40. I think that LF's recognition of this medical reality, however belated, reflects something of a breakthrough for him and I pay tribute to him. As he gave his evidence, I watched his eye contact with the mother. I sensed, if I may say so, that the mother was entirely supportive of the father's concession but may well have come to this recognition a little earlier. Accordingly, I was able to make a declaration on 8<sup>th</sup> December 2021 at the conclusion of the father's evidence, that CPR was not in G's best interests.
41. On a practical level that took away one of the central issues that the court had been invited to resolve at this hearing. Another issue was the continued situation of the central venous line ("CVL"). Logically, to my mind, once it had been recognised that CPR was not in G's interests, the presence of the central venous line became unnecessary.
42. I heard from Dr B and Dr C, Consultant in Paediatric Respiratory Medicine, Sleep and Long term ventilation (LTV) on this issue. Dr B, who has struck me throughout as entirely sensitive to the views of the parents, explained that the continuing presence of the central venous line runs the real risk of infection and sepsis whilst offering no medical benefit. It is contrary to G's identified best medical interests, she argues, to leave that line in situ unless there is any realistic identified basis for it. She told me that any antibiotics or other necessary medication can be administered entirely effectively through a peripheral line, sited temporarily in the arm and then removed after the need for its use has concluded. The peripheral line is minimally intrusive and, as indicated, temporary. The risk of blood infection or sepsis could be 'catastrophic' for G.

43. Dr B noted, and I agree, that LF's grasp of the medical issues of this case is impressive. He has lived in accommodation provided by the Hospital for at least 8 years (with his partner). He visits his daughter in the hospital every day and he manifestly researches her condition extensively. There is absolutely no evidence at all supporting the maintenance of the central venous line and so it is difficult to rationalise now having made the acknowledgement that attempting CPR would be inappropriate, that LF should continue to oppose the removal of the CVL. In my assessment his is an entirely understandable but essentially emotional reaction.
44. In the context of G's situation, the removal of the CVL, as has been observed, signals to LF that his daughter is in *'the last stage of her life'* to use Dr D's phrase. Dr D is a Consultant in Respiratory Medicine and Clinical Lead for Ventilation at B NHS Trust. He has over 25 years' experience of managing long-term ventilation in the community and 12 years' experience of dealing with tracheostomy ventilated patients involved in the transition from child to adult medicine. I found Dr D's approach, like that of his colleagues to be both sensitive and informed.
45. The underlying problem, as LF perceives it, is that, in his view, the removal of the CVL takes away the opportunity for G to have treatment escalated. He considered that there might be some vital treatment that could not be administered without a central line in place. In his statement he identified these as "inotropes" or a "fluid bolus" for which a small peripheral line is not adequate. I record his evidence on this not only to examine his proposition but to highlight the medical lexicon which suffuses LF's evidence. He is steeped in the language of both medical treatment and care management. It reveals the restricted and intense environment which he has been living in for so long. None of the clinicians could support his position, though each of them engaged with it.
46. It had not apparently been planned that I would hear the evidence of G's mother, but as I have already indicated I could not contemplate determining the issues in this case without hearing from her. Her use of language was entirely different from LF's. It was the language of ordinary day to day inter-relationship between mother and child. Her evidence, and this is not a criticism of LF, brought G into this courtroom in a way that the technical language of medicine and care management had failed to do. Not only do this mother and father differ in their use of language, but their language also actually reflects their very differing roles. M rarely goes into the hospital. She takes very little, if any, involvement in G's medical care. She sees her role as *'providing fun for her daughter'*, which she does in abundance. Most days and in all weathers, M and LF take G out of the hospital for very lengthy periods, usually around 6 hours. As has been noted this is another atypical feature of G's hospitalisation. Virtually all the children in the hospital are far too sick for this to be a possibility.
47. M arranges *'spa days'* and *'girly events'* as she termed them. She goes to great lengths to see that G's hair and clothes are attended to and in a glamorous way. LF happily participates in all this and I have seen many photographs of their various activities. By contrast, LF is at the hospital every day, often early in the morning and participates in G's medical care. It is a facet of the hospital's philosophy, to encourage such parental participation. However, there has been a concern, gently and respectfully articulated at this hearing, that LF should be so intrinsically involved with his daughter's catheterisation, given that she is now 27 years of age. I emphasise, as did the hospital, that there is no suggestion of anything inappropriate occurring. What I sensed was a general feeling that whatever G's level of functioning, something of her dignity as an

adult is compromised by her father being responsible for this very intimate aspect of her care.

48. In fact, for reasons that I need not burden this judgment with, LF is the only person involved with the catheterisation. None of the nursing staff participates. This has been the arrangement for some years now. It is a feature of the history that since LF took on this role, there has been no further urinary infection. Beyond recording this, I do not propose to make any judgement. It strikes me that this should be kept in review as the plan progresses with the hope that it moves forward by sensitive negotiation on both sides.
49. The real issue remaining between the parties is the question as to whether G may move from the hospital, which has been her home for so long, to the bungalow rented by her parents (as they would wish) or to nursing home accommodation, 'A Home', as the preponderant evidence suggests.
50. I have been told something about the nursing home. It is a modern property, being about 5 years old. It is approximately a 10-minute drive to the nearest hospital. It consists of a central entrance area with a 'wing' on each side and has two storeys. Though the layout is referred to as having 'wards', they are separate units affording privacy to residents.
51. The patients with the most complicated needs are accommodated on the ground floor with greater access to the supportive technology. The rooms have windows open onto the garden areas. The patients are nursed on a 1:1 basis and, ordinarily, if a patient goes out of his or her room, they will be accompanied by two staff trained in managing patients with a tracheostomy.
52. The carers are all experienced with the techniques required in ventilatory support. They are familiar with G's present ventilation arrangement as well as that which is proposed, by way of change, in the future. They have a nurse manager on site during the day. There are a further 2 registered nurses on site in the day and 1 at night, every night. There are at least another 2 non-clinical managers on site during the working day.
53. I was told, in evidence, that the home has what are termed "clinical governance arrangements" in situ, which ordinarily do not permit clinical care to be undertaken by families. Indeed, ordinarily, families would be asked to go to the family waiting room whilst clinical care is undertaken. But I was pleased to hear that the home was receptive to the bespoke needs of patients and flexible in their arrangements. For many years now, LF has been heavily and intimately involved with G's care. For the past 2 years, as I have said, he has been solely responsible for her catheterisation. I have been informed that, the home would be prepared to continue this level of involvement and to encourage M to become more involved in order that when or if G was reunified with her parents, she would be better placed to manage the burden and privilege of caring for her daughter.
54. M has contemplated, as inevitably she must, being involved in the practical day to day care for her daughter when she returns to live with them. Whilst I did not doubt her commitment to this role, I did sense a general lack of confidence in undertaking it. M has quite a lot to learn in this sphere. On this, all agree. Dr B told me that the axis of the mother's life would change very considerably. She alluded to the loss of privacy

which would be caused by having carers permanently at home with her. The clear division that presently exists between family life and medical care would, inevitably, elide. Both parents rather scoffed at this evidence, but I am bound to say that I was struck by how different M's life would become if she were practically involved in her daughter's day to day care in the way that it is contended, she should be. M is a beautician by profession. She takes great care in her own appearance as well as her daughter's. She and LF go regularly to the gym. G is also carefully dressed in fashionable and designer clothes. I think that Dr B was correct to emphasise the seismic change likely to occur in both parents' lives if it is possible for G to return to their care. Further, I think she correctly identifies that the change would be felt by M particularly strongly.

55. It is said that the staff at the home will be pleased to welcome G, and will have a structure in place to accommodate her swiftly, some time at the end of January 2022. They consider that there should be a clear 'Resuscitation Plan' in place which reflects the reality of G's present circumstances. G has an irreversible condition and is moving to the later stage of her life, no matter how long or short that be. They signal, and rightly so in my judgement, that what should happen in the event of a crisis must not be left to chance but requires to be planned. The objective here is to spare G avoidable pain, distress, or compromise of her dignity.
56. LF has been particularly resistant to the plan for G to move to A Home. His case has been articulated by his counsel, Mr McKendrick QC, with great fidelity to his instructions and with characteristic sensitivity. Properly analysed, LF's reaction, in my assessment is essentially visceral, borne of panic, apprehending and understandably so, a diminution of his day-to-day involvement in his daughter's life. Though I consider his objections to be driven more by fear than by reason, I have no doubt at all that it is motivated by his concern for his daughter's welfare. It reflects LF's unconditional love for his daughter. In the witness box, LF did not really engage with the competing evidence. He could not identify the balance that requires to be struck between the two alternative plans. The door was simply closed in his mind to any advantages that the home might have to offer or, more importantly, how a full assessment of G's needs, outside the hospital setting might ultimately strengthen the prospects of a reunification with her family.
57. That does not bode well for the future, but I hope will not be a blockade to the objective that LF truly desires. What he wishes, of course, is to have his daughter come back and live in a home where he and his partner can care for her. As I have said, in the unprecedented and highly artificial circumstances in which this family has been living, they have negotiated a degree and quality of family life which is to be regarded as central to G's welfare needs. Those whose task it is to plan for, and finance G's future care arrangements must not assume that because G has been a patient in the hospital for 13 years that she must therefore have been in institutional care or indeed that she has become institutionalised. That would be a superficial analysis which failed to understand either the nature of the medical care she has been receiving or the huge input of this family on a day-to-day basis. As I have been at some pains to highlight, most days and for most of the day, G has been with her parents. They are her most effective conduit for communication with the outside world.
58. G's unique living arrangements have not permitted the nursing staff or indeed the doctors fully to assess and understand what G's capacity to communicate might be and

what her true relationship with the outside world is. Given that she has been in the hospital for 13 years, that in itself highlights the quite extraordinary nature of the arrangements that have been in place. Though the clinical team are more pessimistic than the parents, in their assessment of her functioning, I remind myself that from G's earliest years a dissonance was identified between her restricted development and her comprehension of the world around her. I do not assume that her progressive deterioration has necessarily altered this. It will require further and ongoing assessment. That may not be formal in nature and may simply require some more detailed professional observation.

59. In the course of exchanges with counsel I was referred to a decision by Hedley J in **Re LBH (A Local Authority) v KJ & Others [2007] EWHC 2798 (Fam)** where he made the following important observations:

*“It is usually strongly conducive to the welfare of a seriously disabled child to be brought up in a family with siblings. (Not least is that an advantage because thereby family is preserved beyond the death of parents). In those circumstances a disabled child may have to accept that the promoting of the emotional needs within a functioning family may involve some detriment in the achievement of their maximum personal potential. It is well recognised that sadly this tension between needs of family and disabled child is all too often destructive of family life and relationships.”*

60. The reasoning in this passage resonates here. By parity of analysis with the above, the emotional benefit to G of being able to live with her parents cannot be underestimated. In my view, it is of magnetic importance. Hedley J is not merely correct but morally courageous when he identifies the invidious trade-offs that may need to be made between competing and fundamental needs. G's pressing emotional need to be within her family may only be capable of being realised at the detriment of some other facet of her care. An elevated risk to her physical wellbeing, perhaps even to her life expectancy, may be necessary to achieve her countervailing need to be with her mother and father, who have been the constants in her life. Along with her grandmother and her sister, it is the touch of M and LF in which G finds instinctive and irreplaceable reassurance. It is their love she absorbs on a day-to-day basis. The evidence tentatively suggests that it is her family with whom G makes the greatest effort to respond and engage. I should record that this invidious balance was not one either parent felt able to address, for reasons I entirely understand.
61. G has been loved, and on a practical and emotional level, extremely well cared for by her parents. She has also received medical care of the highest standard. The combination of the two has no doubt contributed to the fact that G has significantly surpassed her original life expectancy. However, it is extremely troubling that notwithstanding these very significant positives G's treatment plans have fallen short of what she requires and is entitled to. This has arisen in direct consequence of LF's forceful opposition to clinical advice. It has led to a situation where G has been unsafe and exposed to avoidable harm. It is also necessary to record that in such circumstances where it became clear that agreement was not possible with the parents and where their objections had no medical validity, an application should have been made to this Court some considerable time ago. Failure to do so here, was a failure to protect their patient

and could have had very significant and harmful consequences for her. An adult who lacks capacity is not a chattel of a family member. Parents, however loving they may be, cannot always be assumed to articulate the wishes and feelings of their child. Their own anxiety and distress may, paradoxically, mean that they are sometimes the least well equipped for this task. Neither is their perspective as to G's best interest to be regarded as having greater weight or authority than that of the clinical team. The obligation is to listen to and endeavour to understand the family's concerns but they must never be allowed to stand in the way of necessary and appropriate medical care. Here, they were permitted to do so.

62. The compelling consensus of medical evidence establishes, with great clarity, that G has required a plan which sets out a clear 'ceiling' for her medical treatment, at least since 2016. Dr B agrees with all this and I think has become increasingly perplexed as to how it was prevented from being put in place. It is not necessary for me to explore that in this judgment.
63. Up until this week the plan in relation to CPR as set out in the ReSPECT form was an unsatisfactory compromise, expressed in language which set out the views of the parents and the views of the hospital. It was a study in confusion. It provided no clarity for the treating clinicians and served to stifle G's voice. Indeed, I was told that notwithstanding the fact that the form was intended to communicate to the treating clinicians that CPR should not be attempted, it was more likely that the exact opposite would have occurred. It is a mark of Dr B's integrity that she should express herself with such candour, but she identifies a wholly unsatisfactory scenario. She considered that if LF had been present at cardiac arrest, he would have pressed this ambiguous document upon the treating clinicians in order to encourage CPR. That would have been painful and wholly contrary to G's interests as LF now recognises. Dr B had little doubt that LF would have persuaded the clinical team of the correctness of his view. There can be no further ambiguity in the documentation. Treatment plans are not compromise agreements; they require clarity.
64. Whilst I have recorded LF's position in relation to the removal of the central venous line (CVL), it is important to highlight that this has been, in the view of Dr Andrew Bentley, Consultant in Respiratory and Intensive Care Medicine, in situ for far too long and, once again, entirely in consequence of LF's opposition. Dr Bentley considered that removal of the intravenous fluids, followed by the removal of the broviac line would both reduce clinical risk and enhance the potential for G's care in the community. Additionally, both Dr Bentley and the treating clinicians considered that whilst the presence of the CVL offered no benefit, it had the countervailing disadvantage of presenting a real risk of sepsis. To make the point starkly, at the time of this judgment, the CVL is still in situ with the identified risk as yet unaddressed.
65. As the evidence has evolved it is clear that all the professionals involved in G's care recognise that if it is possible for G to be cared for in her home placement, she should be. In different ways each of the professionals has had to evaluate a situation which is unprecedented in their experience. A 13-year hospital admission is vanishingly rare, and so, I suspect, it should be. What is required now is to achieve stability for G, to 'reset boundaries' as it has been termed. G requires the weaning of medication to facilitate her transition back into the community. Her situation is fragile, and she needs prompt access to the multidisciplinary team in the transitional process. Dr Bentley described this move as '*a leap of faith*'. He was very clear that this '*enormous step*'

required what he termed, '*a step down in order to smooth out the transition*' to any return home.

66. Dr Bentley reviewed the alternative care plan presented by the parents. That plan can best be described as tentative, at this stage. It is incapable of being put in place for a number of months. It is vulnerable to the limited availability of agency workers. In addition, each worker will require full training. Support staff have to be identified and are presently available in very small numbers. The unpredictability of the COVID-19 virus on the availability of carers is also a relevant consideration and likely to be so for some months, perhaps longer.
67. Dr Bentley considered that the experienced nursing home was, by some measure, the '*most appropriate environment*' for her. He describes the A Home as having a '*robust staffing structure*' with highly qualified specialist nursing staff securely in place. Having met G and reviewed the notes, he emphasised the importance of focusing on the complexity of G's needs and the duration of the time she has spent in the Claimant's hospital. He was of the view that an immediate move home would from '*a medical and safety point of view*' be inappropriate. He plainly regards A Home as a stepping stone to eventual rehabilitation to the parents' care. As he put it, the transition is a plan crafted to '*break the fall in terms of her ultimate discharge home*'.
68. Dr D was entirely of the same view. He expressed himself in clear terms. He referred to '*the jeopardy of [G's] discharge*' and to the '*extremely complex*' breadth of her medical needs. He also, properly in my view, identified the importance of achieving what he called greater '*functionality*' in the relationship between professionals and family. This said, he emphasised that the love and commitment of these parents requires to be kept sight of. In simple terms, in a phrase which he repeated on a number of occasions, Dr D considered that G was likely to be '*overwhelmed if she were discharged straight home*'. He told me in evidence that it was important that G's team have full autonomy to deliver her care package, whilst respecting LF's practical contribution and insight. Though, I did not sense the parents were absorbing what he said, Dr D was also emphasising that G's family need to '*gain confidence in the team*' in order fully to unlock their own role at home as a family. In order that both parents hear it clearly and unequivocally, I consider this perhaps more than anything else is the gateway to G's return to them. Ultimately, the decision to walk through it is theirs. I am confident that all involved with G would encourage them to do so.
69. As the CCG are unprepared to pay the cost of a move home at the moment, there are logically only 2 options i.e., A Home or continuing to stay at the hospital. I am very clear that the hospital for this young woman is an entirely unsuitable place for her to live. It has not been necessary for me to analyse the application of the facts of this case, in the context of the judgment of the Supreme Court in **N v A (CCG) and others (supra)**, because I am also persuaded that a return home without the period of decompression and readjustment, as has been identified, would simply not be in G's interests. It risks failure of a magnitude that threatens her comfort, stability and happiness in this late stage of her life. That is quite simply too much to risk. I also anticipate it will take both parents a little time to readjust to what will be a dramatic change in their own lives but I am confident that their lode star will be their daughter's wellbeing and I hope that will enable them to give this plan their fullest and indispensable support.



70. Dr D did not have the benefit of hearing G's parents give evidence, but presciently and insightfully, he observed, as I have already foreshadowed, that their obligation now, if they are most effectively to harness their strengths, is to focus on their role as a family.
71. Mr McKendrick has advanced what I will call the 'home care package', with complete fidelity to his instructions. I have ultimately had very little hesitation in coming to the clear conclusion that that would not, at this stage, be the right plan for G. It is fretted with risk. It has the very real danger that it might set G up to fail. Were it to do so, it is probably the case that she would have no further chance to return to her parents' care.
72. There must be a recognition that the timescales contemplated for the future plan must be driven wholly and entirely, by a clear identification of G's needs: it is necessary for her to readjust to life outside the hospital environment; it is important to stabilise her medically; it is essential that the relationship between the treating clinicians and the family (LF in particular) becomes fully functional; allied to this last point is the need for clear and unambiguous planning which all understand and are committed to; it must be understood, at all times, that G's relationship with her parents is of paramount importance to her as well as to them; notwithstanding this extensive period of hospitalisation, G has enjoyed a high quality of family life which must be preserved in her new environment, recognising that this will involve significant changes for her.
73. I repeat again, that G is surrounded by doctors and nurses who are highly professional and committed to her care. That says a great deal about the professionalism of all those who have been involved throughout and who it is contemplated will be involved in the future. But it also says something about G herself, who inspires and generates this commitment. I add my voice to those of the other professionals who have paid tribute to the love the parents have given, to the day to day stimulation that brightens her life, to their ambition for her in the face of her challenging circumstances. I have already recognised and reiterate that whatever her needs may be across those spheres that we've been investigating, the warmth of their love and the comfort of their touch is perhaps the most important of all.
74. It has not ultimately been possible to move forward by agreement at this hearing, but sight should not be lost of the convergence that there has been, the recognition most importantly of where G is in her life cycle at the moment. What that means, and what it does not mean. She is entitled at this stage in her life to peace, privacy, dignity, the love of her family and the avoidance of avoidable pain or discomfort. On each day, the priority of those needs will change, but collectively if they are focused upon by all they should, I hope, guide the way forward. I hope that if the case comes back before me, it comes with an agreement, with consent as to the way forward. I will keep my fingers crossed for all of you.
75. I record by way of postscript that I have seen all the photographs that the parents have presented in their evidence and I have also watched the videos of LF with G, outside of court. All those involved in G's care should, in my view, watch those videos, they strike me as having the potential to throw some light on G's understanding of the world around her and her capacity to interact with it.

