Neutral Citation Number: [2023] EWHC 2798 (Fam)

Case No: FD23P00452

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
IN THE MATTER OF THE INHERENT JURISDICTION
IN THE MATTER OF INDI GREGORY (d.o.b. 24.02.2023)

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 8 November 2023

Before :

MR JUSTICE PEEL

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Between :

NOTTINGHAM UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Applicant

and

(1) INDI GREGORY (by her Children's Guardian)
(2) DEAN GREGORY
(3) CLAIRE STANIFORTH

Respondents

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Conrad Hallin (instructed by **Browne Jacobson LLP**) for the **Applicant**
Katie Scott (instructed by the **Cafcass Legal**) for the **First Respondent**
Bruno Quintavalle (instructed by **Andrew Storch Solicitors**) for the **Second Respondent**
The **Third Respondent** did not attend and was not represented

Hearing date: 7 November 2023

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Judgment

This judgment was handed down remotely at 2pm on 8 November 2023 by circulation to the parties or their representatives by e-mail and by release to the National Archives

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MR JUSTICE PEEL

Mr Justice Peel:

1. I am again concerned with IG. Before me is an issue about where extubation of IG should take place, and the implementation of a compassionate care plan thereafter.

2. After some dialogue, the position of the parties was clarified:

    a. The Trust says that IG should be extubated at a named hospice, or in the hospital where she is a patient; her parents can elect which. Such extubation should take place by 12pm (noon) on Wednesday 8 November 2023. The Trust would endeavour to stabilise her after extubation and assess the next step, a process which they think could take a week or so. They would determine whether there are clinically available options for her compassionate care, and present such options to the parents. In other words, the Trust would be charged with determining the options, from which the parents could make an election. If clinically justified, the options could include a return home.
    b. F (supported by M who did not attend, but is aligned with F) says that IG should be extubated at home, and then remain there.
    c. The Guardian supports the Trust's position.

3. I do not need to rehearse the background in detail, which is set out in two previous judgments of mine, as well as a judgment of the Court of Appeal.

4. By order dated 16 October 2023, I authorised withdrawal of invasive treatment for IG in accordance with a care plan which I approved. F's application for permission to appeal to the Court of Appeal was refused after an oral hearing. A further application to the European Court of Human Rights was deemed inadmissible.

5. My judgment of 13 October expressly recorded at para 44 that:

    "I am quite sure that the Trust will, as they say, do everything they can to care for IG with compassion, providing her with treatment to alleviate pain, and making her as comfortable as possible. That can take place at home or at a hospice, as the parents may elect."

6. The care plan stated:

    "Location of care
    Parents should be supported to decide where compassionate care would be best delivered. Options include a hospice, the hospital, or home".

7. It is, I think, right to observe that there was very little focus at trial upon this aspect of the care plan. The parents thought it meant they could elect to take IG home, even if not deemed clinically appropriate. The treating clinician from whom I heard evidence today understood it to mean that the Trust would present clinically appropriate options from which the parents could make a choice; he did not take it to be a carte blanche for the parents.

8. It is that misunderstanding which has led to the issue before me.

9. On 30 October 2023, at a time when the Trust had made preparations for transfer to the hospice for end-of-life palliative care as had been elected by the parents, and just before extubation was due to take place, F applied, in essence, to take IG to a hospital in Italy for treatment there. I refused the application, and again the Court of Appeal refused Permission to Appeal, this time on the papers.

10. On 1 November 2023, after I had refused the application, but before consideration of that decision by the Court of Appeal, the parents wrote to the treating clinicians saying that they would like the care plan to be implemented at home, rather than in a hospice.

11. On Friday 3 November 2023, the parents again wrote saying they wished for IG to be transferred home (in the event that the Court of Appeal decided against them). It seems clear that in this period the Trust had decided that a home transfer would not be appropriate, but did not communicate this, partly because the Court of Appeal decision was pending. It also seems that communication between clinicians and the parents has become more challenging, although I understand they had a lengthy discussion on 6 November 2023 about these matters.

12. The Court of Appeal refused Permission to Appeal on Saturday 4 November 2023. By their order, the stay on implementation of the care plan expired at 2pm on Monday 6 November 2023.

13. On Monday 6 November 2023, approximately 2 hours before expiry of the stay, I received an email on behalf of the parents stating that they/the parents had received no response to the communications about the transfer of IG to the family home. The Trust by email responded saying that home extubation was no longer appropriate because of deterioration in IG's condition.

14. I convened a hearing that afternoon at about 3pm. I then listed a further hearing at 10.30am on Tuesday 7 November 2023.

15. Overnight, I received the following:

    a. A joint witness statement from two treating clinicians, one of whom is Dr E, who gave evidence to me at an earlier hearing.
    b. A statement from F.

16. It seemed to me that I should treat the dispute as an application by the Trust in essence to implement and/or vary its care plan, albeit no formal application has been made. It also seemed to me that I would need evidence from the Trust.

17. As before, in my judgment this is essentially a best interests decision, just as it was in **Manchester University NHS Foundation Trust v Fixsler [2021] EWHC 2664**

(Fam) where MacDonald J was faced with a similar issue about the location of end-of-life care. I have previously rehearsed the law on best interests, and do not propose to repeat my analysis.

18. I do not accept, as was pressed upon me by counsel for F, that the applicable test is set out by Poole J in **An NHS Trust v AF (by his Litigation Friend the Official Solicitor) and SJ [2020] EWCOP 55** at para 22, namely that the Trust must demonstrate a material change of circumstances to justify a change to the care plan. That case was about revisiting earlier findings, and the making of alternative relief, an appropriate test for the hearing before me on 1 November 2023. But it is not appropriate here. Nobody is asking me to revisit my findings. The relief sought relates to implementation of my substantive order, not to undo my conclusions about life sustaining invasive treatment. It is for resolution of a misunderstanding arising between clinicians and parents from my original order. I have already determined that the Trust is entitled to extubate; now I have to decide how and when that takes place. In my judgment, and in fairness to F's counsel he did not demur, although any material change of circumstances may well be relevant, the test remains one of best interests.

19. Notwithstanding the arrangement of the hearing at short notice, and the fact that evidence was provided overnight, the Trust, supported by the Guardian, invited me to proceed with the hearing. Mr Quintavalle on behalf of F indicated he would need a little time to digest the clinician's statement which I readily acceded to. He flagged up that he might apply for an adjournment to enable F to obtain medical evidence of his own on this.

20. When we resumed, I decided to hear the evidence and submissions, and consider at the end whether further evidence should be obtained. Nobody dissented from this. In adopting this course, I had in mind the urgency, the fact that there have been a number of delays in these proceedings, my findings about the high level of pain and suffering experienced by IG, and the intimate knowledge of this case on the part of the clinicians, F and F's legal team.

21. In considering this application, I must look at all matters in the round, with attention being paid to any change of circumstances which is of particular relevance. I have been alert throughout to consider what, if any, additional evidence might assist.

22. At the end of the hearing, F submitted that there should be an adjournment of a few days to allow for further exploration of evidence. He flagged up that F might (but might not) apply to adduce further evidence, including expert evidence. I have decided against that course of action:

    a. It would involve delay which in my judgment is inimical to IG's best interests, as every passing day brings more pain and suffering. I do not consider that there is the luxury of a further adjournment.

b. I already have a very substantial body of evidence which I have seen and heard from previous hearings. I heard today from Dr E whose evidence I have accepted in the past.
c. The clinical team, in my judgment, are well placed to give an informed view about these issues. They know IG well, and are likely to have a clear sense of the risks and benefits of extubation at home. Unless I have reason to doubt what they say (which I do not), it is hard to see who could realistically offer a better perspective.
d. The issue in the end is narrower than at first appeared; it is about the location of the actual extubation and immediate aftermath. Extubation itself is not opposed (nor could it be, given my previous findings). This is an important issue, but relatively circumscribed.

23. I should emphasise that before, during and at the end of the hearing, I considered whether there was any gap in the evidence which needed to be filled, and whether it is necessary for an expert to report on this issue. I have decided that it is not necessary.

24. In my first judgment, I accepted the evidence of the Trust (in particular Dr E), and commented that:

"…the clear impression I have of the treating team as a whole (including Dr E) is one of the utmost skill and dedication devoted to the care of IG."

25. The joint clinicians' statement was supplemented by the oral evidence of Dr E. They say in summary (and I accept their evidence):
a. IG remains critically unwell, and is clearly distressed, agitated and in pain.
b. In theory extubation, i.e the removal of the breathing tube, can be carried out anywhere. She is now ready for extubation.
c. The main challenge is the extubation aftercare. It has to be managed by trained professionals with resources on hand to deal with complications, and minimise distress.
d. It is not possible to predict how IG would present after extubation. She may (and hopefully will) stabilise. After perhaps a week, it will be apparent how well she has stabilised. The Trust will then offer the parents clinically appropriate options which might include going home. Alternatively, she may not be able to go home from a clinical perspective; it all depends on her presentation and needs.
e. If she goes home, a package of care can be provided depending upon her needs.
f. IG has a complex medicine schedule involving oral and subcutaneous controlled drugs. Delivery thereof is highly skilled, and requires nursing care with a particular level of training.
g. IG is on feeds which are delivered by specialist equipment.
h. Since 9 October, IG has had continuous sedation. Thus, the process of weaning her off sedation must be done carefully by skilled practitioners to avoid the complications of withdrawal abstinence syndrome, symptoms of

which include distress, agitation, vomiting, diarrhoea and fevers. She is highly dependent on sedation and therefore now much more at risk.

i. IG is currently too unstable for non-invasive ventilation in the community.
j. The consequence of the delays since the original application, and my first order, is that the post extubation scenario is much more complex and needs expert management.
k. The only safe way to fulfil the compassionate care plan is with extubation at the hospital, or at the hospice.
l. Dr E's preference is the hospice, which is medically equipped and far better suited to deal with compassionate care, whereas the hospital's main focus is intensive care.
m. On 9 October 2023 a transfer home was just about possible, but on any view very difficult. A 24/7 care package (with two nurses in attendance at all times) would be very problematic to arrange. There was no clear pathway for escalation of treatment. A home assessment would be required." A "huge amount" of equipment would be needed. Care after death would be required.
n. Since then, added complexities include:
    i. The trust would be unable to provide best symptom management in the community given the greater risks associated with withdrawal abstinence syndrome.
    ii. Weaning her off controlled drugs would be logistically very challenging. It is much more difficult now than a month ago because she has been on them for so much longer. Sub-optimal weaning off would heighten the risk of withdrawal abstinence syndrome.
    iii. A month ago, post extubation it was less likely IG would have needed non-invasive ventilation. Now, by contrast, she is much more likely to need it and, because of her instability, cannot presently receive it in the community.
    iv. Now (unlike a month ago) round the clock specialist nurses who are expert in these various aspects would be needed. It is, however, unlikely they would be available. To arrange a package of this sort would take at least a week (if possible at all), and cause further delay. Dr E accepted that no specific enquiries had been made but he was able to draw on his general experience and I see no reason to doubt what he said.

All of these, it seems to me, combine together in a material change to her circumstances over the past month, and directly impact the question of whether extubation at home is feasible.

o. By contrast, the above can be provided in hospital, with provision of care from the team who know her very well. The downside of the hospital setting is that it is not suited to palliative care; its main focus is intensive care.
p. An identified hospice is still willing and able to take IG, with a same day transfer. The hospice can provide a bespoke environment, a complex management plan, and 24/7 specialist care. The main risk is the actual transfer itself, but mitigating steps can be taken by a specialist transfer team.

26. F told me that he understood from his conversation with the hospice that the extubation aftercare provided by the hospice would be the same as that which would be provided at home. Whatever F might have been told, Dr E was very clear, and I accept his evidence that this is not the case. No doubt this conversation has heightened F's general concerns. He would like IG to go home but, failing that, extubation at the hospice would be preferable. He suggests the family could manage some of the care themselves. As before, I thought he was very composed and dignified in heart rending circumstances.

Analysis

27. In short, I accept the evidence of the clinicians. The wishes of the parents are a powerful consideration but not the only one. The presentation of IG is more complex than it was when the care plan was drawn up in terms of extubation aftercare. There are a number of factors which render extubation and palliative care at the family home all but impossible, and certainly contrary to IG's best interests. It is too dangerous to do so given the clinical complications. I have to say that I am dubious that even at the hearing before me in October, extubation at home was clinically appropriate, but in my view, it is clearly not now, for the reasons given by Dr E. The requisite expert nursing staff cannot be easily arranged. The medical risks are significantly enhanced as a result of the delay since my original order in October. The potential harm to IG of complications and sudden agitation would be increased. The likely delay of arranging a care package at home would lead to ongoing pain and suffering. The hospice by contrast can receive IG straight away. In my judgment it is not in IG's best interests for extubation to take place at home.

28. I consider it essential that IG should continue to have clinical treatment of the highest quality, carried out in a safe and sustainable setting. That will not be available at home. I do not think, with the best will in the world, that it is practical or appropriate for the parents to take on the burden of substituted nursing care. It may also be that for the plan to work at home, there needs to be a close, constructive and engaged level of communication between the parents and the Trust/relevant clinicians, but, unfortunately, that does not appear to be the case. The sad fact is that IG continues to suffer, and a transfer home carries with it an unacceptable risk of precipitate events and consequential increased suffering.

29. In my judgment, the care plan should be amended in the manner sought by the Trust. Ultimately, compassionate care will be driven by what is clinically available at the time. That will be a matter for the clinicians. At present, a hospice setting remains available and extubation should take place there unless the parents elect that it takes place at the hospital. The Trust is authorised to effect such extubation no earlier than 2pm on Thursday 9 November 2023. Thereafter, the clinicians will be entitled to decide on IG's compassionate care and, where they offer options, the parents may so elect. The parents cannot make the clinical decisions. This is consistent with the approach referred to at para 50 of **R (Burke) v General Medical Council (CA) [2006] QB 273**. The lengthy (in the context of this child) delay since my first

judgment has led to the inability to provide a home environment. I hope now that the extubation can take place with constructive engagement.

30. Finally, IG has very recently been granted Italian citizenship. F acknowledged, correctly and properly, that my decisions and orders are unaffected by this development.

MR JUSTICE PEEL
Approved Judgment