Neutral Citation Number: [2019] EWFC 86

Case No: FD1900293

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 26 June 2019

Before :

MR JUSTICE MOOR

- -

Between :

A South East Trust	**Applicant**
- and -	
AGK, GFM	**Respondent**

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- -

MR J MCKENDRICK QC appeared on behalf of the Applicant

MS E JOAO-MANUEL appeared on behalf of the Respondent AGK

MS K RICHARDSON appeared on behalf of the Respondent GFM

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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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MR JUSTICE MOOR

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.

Mr Justice Moor:

1. I am dealing with a very serious matter concerning a young man, AGK, born in 2002, so he is 16 years of age, although he will soon be 17. He has a strong faith as a Jehovah's Witness. He was born in Africa. Initially he lived with his mother and was estranged from his father. Tragically, his father died in 2008. For reasons that I do not entirely understand, his mother then disappeared without warning, and he was brought up by his elderly paternal great-aunt.

2. It was clear that, despite the fact that he was doing very well at school in a country in Africa, caring for him was becoming too much for his great-aunt. His aunt, GFM agreed to care for him. GFM resides in the South East of England, where she has lived since around 1992. An application was made to the Circuit Court in the country in Africa on 13 June 2016. GFM was granted legal custody of AGK, but, inevitably, that gave rise to issues about entry visas to this country.

3. In March 2019, AGK was granted an entry visa with indefinite leave to remain until 2024. He came to the United Kingdom earlier this year. On 7 May 2019, he presented to a GP with a fever. He was diagnosed as suffering from Acute Lymphoblastic Leukaemia, ("ALL"). He was sent to a South East Trust for treatment.

4. Because of his religion, he and his entire family oppose the use of blood products to treat his illness. In consequence, on 5 June 2019, the NHS Trust applied to this court for declarations as to what was in his best interests. It is right to say that, from the very beginning, the Trust has taken the view that it would not be in his best interests to treat him with blood products against his fundamental objections.

5. The Trust did say that its position might have to change, depending on further tests. It accepts in the application that AGK is Gillick competent. The difficulty for the Trust has been that there may come a time when blood products are necessary to save his life. On 5 June 2019, the Consultant Haematologist, provided a statement, which gave the history of the matter and said that AGK was being treated on what has been described as regimen A.

6. There are three regimens for the treatment of ALL: A is the lightest treatment. B is the medium treatment and C is the heaviest treatment. I understand that treatment with regimen A is usual for children under the age of 10. For a child in AGK's position, it would normally have been treatment B. However, AGK's initial responses to regimen A appeared to be very good. It was hoped that his bone marrow assessment on 14 June 2019 would show complete morphological remission.

7. The very detailed statement makes it clear to me that one of the differences between regimens A, and B and C, is that B and C involve the use of a particular drug called Daunorubicin, which is a greater suppression of the bone marrow. This makes it more likely that there will be a need for the transfusion of blood products if the platelets or the red blood cells fall too low.

8. The statement makes it clear and I accept entirely that AGK has a maturity beyond his years. There is no evidence whatsoever of coercion in relation to his views. He believes it was a miracle that the Home Office approved him to come here when it did, such that he was

able to benefit from the huge expertise of the South East Trust, and that this was a huge advantage to him, notwithstanding his inability to accept blood products.

9. The professor told me that all his treating clinicians were unanimous that they should not treat him against his wishes; that to do so would be an assault on him; and that it was not medically justifiable. I was told that this was a unanimous view which is unusual. I was also told there was concern that it would be very damaging to him both physically and psychologically if he was given blood products against his wishes, and that it might well be completely counterproductive, particularly if he then refused any further treatment at all.

10. The consultant child and adolescent psychiatrist has provided both an opinion for me and a statement. He tells me that AGK is an intelligent, bright, calm and cooperative boy. There is no evidence of mental health illness. AGK has absolute certainty about his decision. The doctor is very concerned about the harmful consequences, both physical and psychological, of forcing him to have blood products against his wishes.

11. AGK filed a statement on 14 June. He told me that he has dedicated his life to Jehovah. He will not violate Jehovah's command to abstain from blood. Turning his back on God would make his life impossible. He is consistent and unwavering in this view. He does not want to die. He wants the best possible medical treatment, including chemotherapy if necessary, but he does request that his refusal of blood products is respected and submits to me it would be an assault if he was treated against his wishes.

12. He says he does not want the ordeal of having blood products forced upon him, even though he knows that Jehovah would not hold it against him if such products were forced upon him. His aunt provided a statement dated 17 June 2019, which is completely supportive of AGK's position.

13. Further tests were carried out on 14 June 2019. A second Consultant Haematologist at the Trust has produced a statement dated 24 June 2019. Regrettably, the results were not as had been hoped. Of course, it is right to say the treatment has had success, but it has not been a complete success, and I am told that AGK does require an intensification of his treatment.

14. The bone marrow was in remission but there was an MRD level of 0.2 per cent, and I am told that there is a risk of the return of the Leukaemia if that figure is higher than 0.0005 per cent. As a result, the standard treatment would be regimen C, but that has an 85% chance of him needing a blood transfusion at some point. Regimen B would be possible; that would lead to a drop of 7% in his survival chances, but the chance of a blood transfusion would still be very high, at 75%.

15. The suggestion from all the doctors is that AGK is treated instead with Blinatumomab, which is a novel antibody treatment, followed by three years of maintenance therapy. It is said that this is not standard care, but there is good evidence that it would be an effective treatment. Apparently, the antibody recruits the immune system to destroy the Leukaemia cells. It involves continuous infusion over four weeks, but some of that can be done from home. There is a 1% to 3% chance of the need for a blood product, which is clearly a far, far lower figure than 75% to 85%.

16. I have been informed about the well-known side effects of regimen C: the nausea, the headaches, the hair loss, the sore mouth, the temperatures, etcetera, and whilst, of course, I

take all that into account, there is no doubt that regimen C is the preferred treatment in this sort of situation. Nevertheless, I am not dealing with a normal situation. I am dealing with deeply held religious convictions.

17. AGK understands that he may die if he needs a blood transfusion, and it is not given to him. He also understands that it would be much harder to treat him if there was to be a relapse, but he takes the view that his life would not be worth living, and he could not go on with treatment if he had a blood transfusion. As a result, the doctor tells me that she believes that transfusing him against his will would not be in his best interests.

18. I have a second statement from AGK, in which he tells me that he is obviously disappointed and concerned that the results do not show a clearance of the illness. He welcomes the prospect of the Blinatumomab treatment. He understands the risks involved, but he is still resolute in his opposition to blood transfusions.

19. Finally, I have a medical report from a Professor of Paediatric Haematology instructed, I believe, on behalf of AGK's aunt. The Professor basically confirms everything that I have set out above. She confirms that regimen A is definitely not recommended due to the extremely high risk of relapse. She says that the best remaining prospect is Blinatumomab treatment and one of the reasons for that is that the necessity for blood product support will be significantly lower. She tells me that, in fact, she has a higher view of the likely need for blood support under regimen C. She puts it at 90%.

20. It is right to say that there have not, as yet, been all the necessary clinical trials and assessments of Blinatumomab, but she believes that, for those people who have had the treatment, there has been an 87% completed MRD response. She is of the view that this treatment is the most pragmatic approach.

21. Of course, my paramount concern is the best interests of AGK, but I have to weigh in the balance a large number of factors. One of these, which is of particular importance in this case, is AGK's wishes in the light of his Gillick competency and his fundamental opposition to treatment with blood products.

22. I am of the view that giving him blood products against his wishes would be counterproductive and damaging to his welfare. I believe that it could have serious psychiatric and psychological consequences as well as physical consequences. I fear that he would lose complete confidence in his treating doctors and that he might, then, withdraw from treatment. That is clearly something that this court should not be risking unless absolutely essential.

23. He is a young man who understands fully the decision that he is taking. I accept that his convictions are deeply held and undoubtedly his own. I am therefore of the view that it would be wrong for me to impose regimen C on him, and wrong to require him to have blood transfusions against his wishes. I am reassured by the fact that the Blinatumomab treatment is available and that it reduces the risk of blood transfusions so considerably. Of course, I accept that it may not work although I fundamentally hope that it does.

24. I wish AGK the very best in this treatment, but I am clear that he goes into this with his eyes open; that all the clinicians and doctors support this Blinatumomab treatment as being the correct way to proceed; and that the slight risks of going down that route as opposed to

regimen C are very significantly outweighed by the serious and very deleterious consequences for AGK, were a blood transfusion to be necessary against his wishes.

25. I therefore have no hesitation in approving the draft order that has been presented to me by Mr McKendrick QC who appears on behalf of the NHS Trust. I declare that it is in AGK's best interests not to receive blood products unless, in the reasonable view of his treating clinicians, it is clinically indicated and he has consented to the same. By making that declaration, I further declare that it is lawful for the Trust to proceed in that way. I also make a declaration that it is lawful and in his best interests to receive treatment for his ALL by way of the provision of Blinatumomab followed by maintenance therapy.

26. Now, of course, it is possible that circumstances may change, and there may have to be a further hearing. That is provided for in paragraph 3, although I make it clear that I have, today, dealt with the most significant issue in the case, and that is the question of treatment by blood products against the wishes of AGK.

27. It is right, however, that the court's door must remain open in this case, given that a young man's life is at stake, but I am of the view that the Trust should not be making applications without at least having given short notice to both the first and second respondents. I accept that there may be exceptional circumstances, in which that is impossible, and, if it is, that fact must be drawn to the attention of the judge hearing the application, as well as the judgment that I have given today. Those are the orders that I make. I will now consider the Press Association's application to name the Trust.

28. It is quite a difficult decision as to whether or not to allow the naming of the Trust. I make it absolutely clear that there is no criticism whatsoever of this Trust in relation to its conduct of this case. In one sense, it perhaps becomes more difficult if there is criticism, as it could be said that the public should know about the criticism.

29. I understand why Mr Farmer asks me to name the Trust. He rightly, I think, says that there is no danger in this case of a Charlie Gard type situation; after all, there is, fortunately, no conflict here, between AGK, his family, and the Trust. Basically, his submission is that it is transparent to name this Trust. It is opposed by both the Trust and AGK himself and by his aunt. I have very seriously considered naming the Trust because I did not think that it was likely that AGK would be identified by my doing so. I have been swayed in deciding not to do so by one fact, and one fact alone, and that is that AGK himself is very concerned about this and the risk of him being identified. I do not want him to be worried, and I do not want in any way to endanger his prospects of a full and complete recovery. For that reason and that reason alone, I am not going to name the Trust. I will describe the Trust as a South East Trust.