

Neutral Citation Number: [2019] EWHC 3033 (Fam)

Case No: FD19P00600

IN THE HIGH COURT OF JUSTICE FAMILY DIVISION

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 30/10/2019

Before:

THE HONOURABLE MRS JUSTICE ROBERTS

Between:

An NHS TRUST

Applicant

- and -

(1) CX
(2) C NHS TRUST
(3) D NHS TRUST
(4) CX (through his Children's Guardian)

Respondents

(MEDICAL TREATMENT: GILLICK COMPETENCE: CONSENT TO TREATMENT)

Ms Katie Scott (instructed by Browne Jacobson Solicitors LLP) for the Applicant and the C NHS Trust

Ms Maria Stanley (instructed by CAFCASS Legal) for the Fourth Respondent There was no appearance by the First and Third Respondents

Hearing date: 29 October 2019

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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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.

Mrs Justice Roberts:

- 1. CX was born in August 2005 and is now 14 years old. He is part of a loving and tight-knit family group which consists primarily of his mother and two elder sisters. In 2009, when he was not quite four years old, he was diagnosed with, and successfully treated for, a particular form of lymphatic cancer. That treatment was successful and he appeared to be in complete remission albeit that he was regularly monitored to ensure that he stayed well and healthy.
- 2. Life carried on successfully and happily for CX over the intervening years. This summer (2019), after experiencing various symptoms, he was taken by his mother to the doctor and referred for various tests. One of those tests was a biopsy which revealed conclusively that his lymphatic cancer had returned, albeit in a different form, which had progressed to Stage 4.
- 3. Since that diagnosis, CX has been treated by a team of consultant paediatric oncologists who have devised an immediate treatment plan which it is hoped will restore him to his previous good health. The case is made more complex because there are no case reports in the medical literature of a child having these two different forms of lymphatic cancer. As a result, there are no established treatment pathways, or guidelines / protocols, which those charged with his care can follow. His treating team has consulted widely both here, in Europe and in the United States of America.
- 4. The treatment plan which has been devised for CX is necessarily one which will be kept under review as his response is carefully monitored. However, in its component elements, the plan is clear in terms of its three stages.
 - (i) CX will undergo two rounds of chemotherapy at one of the applicant's hospitals. This first round of treatment will commence as swiftly as possible. Thereafter a PET scan will show the extent to which he is in remission.
 - (ii) He will then undergo a second round of chemotherapy before being transferred to one of the second respondent's hospitals.
 - (iii) At that hospital he will receive further chemotherapy and stem cell replacement. If this is successful, he will move into a recovery, or rehabilitation, phase. This is likely to take some four to six weeks and CX is likely to spend this time in one of the third respondent's hospitals.
- 5. As a result of the treatment it is highly likely that CX's blood counts will drop significantly. He is likely to need transfusions of blood products. The need for such transfusions is likely to be very high during the first round of chemotherapy and during recovery after stem cell infusion (some 90% to 95%).
- 6. Both CX and his mother are Jehovah's Witnesses. Neither can consent to receive blood or blood products without derogating from their firmly held religious beliefs. Whilst each is willing to consent to the proposed chemotherapy, stem cell harvesting and the return of the stem cells following chemotherapy, they do not consent to that

part of the treatment plan which involves the administration of blood and/or blood products which the doctors believe to be a necessary and integral part of CX's recovery. Indeed, such is the risk to him if blood transfusions are not administered, they do not regard the chemotherapy as a safe option. Without it there is a clear risk that CX's cancer will spread, he will become extremely unwell and his life will be at risk.

- 7. AB loves her son dearly; that much is plain from all that I have read. She has parental responsibility for him and is in a position to provide consent on his behalf to the treatment plan devised by the team currently charged with his care. CX wants to live. But for his illness, he leads a full life amongst his family and the close friends he has made at his school. He will have plans and ambitions as to how he wishes to live his life as he grows into a young man with all the many opportunities which lie ahead. That neither feels able to provide consent to the full treatment plan speaks much to the strength of the religious convictions which each holds. Both have said that they will respect the law and any decision reached by the court if it does not accord with their personal religious beliefs.
- 8. This is the application which now comes before the court. In order to proceed with the proposed plan of treatment, the applicant NHS Trust seeks a declaration that it is both lawful and in CX's best interests to receive blood and blood products as a part of that plan.

The legal framework in which the application is made

- 9. In the recent case of *Plymouth Hospitals NHS Trust v YZ and ZZ* [2017] EWHC 2211 (Fam), [2018] 1 FLR 948, MacDonald J delivered a judgment in which he set out the fundamental principles of law in this area, collected from many of the previous leading judgments including *In Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *An NHS Trust v MB* [2006] 1 FLR 554 and *Kirklees Council v RE and Others* [2015] 1 FLR 1316. I can do no better than to repeat them here.
 - "(i) The paramount consideration of the court is the best interests of the child. The role of the court when exercising its jurisdiction is to give or withhold consent to medical treatment in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment;
 - (ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be;
 - (iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken;
 - (iv) The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one; the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. In reaching its decision the court

- is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests;
- (v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great;
- (vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment;
- (vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive;
- (viii) Each case is fact specific and will turn entirely on the facts of the particular case;
- (ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by their own emotion or sentiment;
- (x) The views of the child must be considered and be given appropriate weight in light of the child's age and understanding."
- 10. CX is 14 years old, as I have said. He is plainly an intelligent child who is more than capable of making many decisions for himself. He decided to confirm the strength of the religious beliefs he had espoused by becoming a baptised Jehovah's Witness. He has taken the time to write me a letter in which he sets out some of his reasons for deciding not to accept blood transfusions as part of his treatment plan. I do not propose to set out the contents of that personal letter in this judgment but I would wish CX to know that I have read it carefully and have taken all that he has said to me into account in reaching my decision. What I do regard as important in this context is CX's clear statement that this is a decision which he has taken on his own account; he was baptised into his faith after much thought and because he wanted to express his love to his God. He has made it clear in his letter that, were I to decide to authorise the hospital to carry out the proposed treatment plan including blood transfusions, he would feel angry and upset because I would be forcing upon him something which he did not want. He has made it clear that he would agree to treatment with blood fractions since that is something which his religion permits. He queries why the doctors are not prepared to try using blood fractions as an alternative to blood products. If full blood transfusions are indeed required in order to ensure his survival, he asks that every effort should be made to give him "as little as possible".

- 11. The view of the Guardian who has spent some time with CX is that he appeared to have "both an age appropriate understanding and awareness of his own unique circumstances". She tells me that "he wants to be well again so that he can live a normal life". That statement of aspiration on CX's part tells me much about the spirit and fortitude with which he is approaching the treatment which lies ahead of him and the value which he rightly places on overcoming his present illness so as to resume all that he enjoyed before the difficult news he and his family received over the Summer.
- 12. In the normal course of events, consent to medical treatment for a child who is under the age of 16 years is given either by his parent in the exercise of the parental responsibility entrusted to him or her by operation of law or, if the child himself is competent to make the decision himself to that medical treatment, by the child himself: see *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112. In that case Lord Scarman confirmed, at 188, that the parental right to decide for his or her child yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision.
- 13. This principle is often referred to as *'Gillick competence'*. Further assistance on its application was provided by the Court of Appeal in the subsequent case of *Re R (A Minor)(Wardship: Consent to Treatment)*, *Re* [1992] Fam 11, [1992] 1 FLR 224. At pages 25 to 26 of his judgment, Lord Donaldson MR explained that the principle of *Gillick competence* has to be seen as a staged development of a normal child. In the context of a simple example, his Lordship said this:
 - "... at one age [a child] will be quite incapable of deciding whether or not to consent to a dental examination, let alone treatment. At a later stage it will be capable of both, but incapable of decising whether to consent to more serious treatment. But there is no suggestion that the extent of this competence can fluctuate upon a day to day or week to week basis. What is really being looked at is an assessment of mental and emotional age, as contrasted with chronological age, but even this test needs to be modified in the case of fluctuating mental disability to take account of that misfortune. It should be added that in any event what is involved is not merely an ability to understand the nature of the proposed treatment in this case compulsory medication but a full understanding and appreciation of the consequences both of the treatment in terms of the intended and possible side effects and, equally important, the anticipated consequences of a failure to treat."
- 14. What is abundantly clear following the Court of Appeal's analysis in *Re R* is that in cases where a child under the age of 16 has been found to be *Gillick* competent, the court has the power to override his or her decisions where it is in the child's best interests for it to do so.
- 15. I was referred in the applicant's written statement of case to the Guidelines published by the General Medical Council. Paragraph 26 of those Guidelines set out the following principles which doctors must consider in these situations:-
 - "It is important that you assess maturity and understanding on an individual basis and with regard to the complexity and importance of the decision to be made. You should remember that a young person who has the capacity to consent to

straightforward, relatively risk-free treatment may not necessarily have the capacity to consent to complex treatment involving high risks or serious consequences. The capacity to consent can also be affected by their physical and emotional development and by changes in their health and treatment."

Discussion and analysis: Gillick competence and best interests

16. In addition to a written statement from CX's mother, AB, I have written statements from two of his treating physicians, Dr SD and Dr DY. Both are consultant paediatric oncologists. In relation to the need to use blood products, Dr SD tells me this:

Risks

- "14. Chemotherapy acts on the cancer cells but also on some good cells in the body, as it is myelosuppressive (suppresses the function) to the bone marrow. It is difficult to be certain, but from our experience of the chemotherapy regimen planned we know that it is very likely that CX's blood counts (haemoglobin, platelets and white cells) will be low at certain time points in treatment. To safely deliver the chemotherapy, we would need to support CX with blood and platelets, if and when needed. Respecting CX's and his family's wishes, we will put steps in place to minimise the need for blood product support (sampling minimum amount of blood when sending to the lab, reducing the number of times his blood counts are checked, giving drugs like erythropoietin to stimulate red blood blood cell production and tranexamic acid to reduce mucosal bleeding, setting lower thresholds for transfusion). While all these steps may reduce the need for blood products, they are unlikely to eliminate it completely.
- 15. Without the option of supporting his treatment with blood products it would not be safe to proceed with treatment. Supportive care is an important part of the treatment plan in children with cancer and helps us deliver chemotherapy effectively and safely."
- 17. In terms of the risks to CX, Dr SD says this:
 - "a. <u>Haemoglobin</u> We would ordinarily transfuse for low haemoglobin at 70 g/litre (guidelines vary between hospitals) or if the patient is symptomatic. We may lower the threshold for CX, but it is important that he feels well. If he is symptomatic with low haemoglobin he may feel tired, have headaches, shortness of breath and may not eat as well. This will compromise his general wellbeing and nutritional status. This in turn will compromise his ability to tolerate chemotherapy and in turn his chances of cure.
 - b. White cell count these will inevitably drop due to the nature of chemotherapy. This will make him susceptible to serious, life threatening infections and he will need urgent intravenous antibiotics if febrile or unwell. In case of severe sepsis, occasionally blood products like fresh frozen plasma or albumin may need to be given to support his care.
 - c. <u>Platelets</u> A normal platelet count is 140 400 x 109 /L (again, there are small variances between hospitals). Myelosuppressive chemotherapy would lower the platelet count and therefore increase the risk of bleeding.

This may be in the form of gum or nose bleeding but can be more serious, e.g. bleeding from the gut or brain. Our normal threshold for platelet transfusion is 10 if well and 20 if febrile. If there are any signs of bleeding or mucositis (sore mouth), we may transfuse at higher platelet levels to try and minimise the risk of a serious bleed.

- d. In summary, blood and platelet support not only help to keep CX safe though treatment, [their use] also helps us to deliver the full dose of the chemotherapy and therefore optimise the chances of cure."
- 18. Dr SD has met with, and spoken to, CX's family. Of his mother, she says that AB understands and clearly loves her son and wants the best care for him. That is a view which I share without reservation. In her own written evidence AB pays sincere tribute to the treatment and care which CX is currently receiving and to the dedication and hard work of the entire team involved in his care. She wants him to have treatment to cure his cancer. I have the utmost respect for AB's religious views and for those of her son. I accept that it is only her belief in her faith which prevents her from giving active consent to the use of blood products in CX's treatment. She makes it quite clear in her own written evidence that she respects the law and will not refuse treatment if the outcome of my decision does not coincide with what she believes.
- 19. In relation to CX himself, Dr SD believes that he is able to understand what is being proposed and why the hospital is recommending the use of blood products. However, she also reminds me that he is facing a daunting and stressful time. As she says, he is a young boy who has had more than his fair share of medical treatment. I share Dr SD's admiration of the strength of character which CX is displaying at such a difficult time in his young life. Whilst initially he appeared to be more accepting of the use of blood products if they were absolutely necessary, his position recently, as Dr SD observes, has become more entrenched in line with his religious orthodoxy.
- 20. Of the ultimate risk, Dr SD is clear in her evidence. Without the support of blood products as an integral element of the treatment plan, the toxicity from the chemotherapy would put CX's life at risk. That is a view shared by her fellow oncologist, Dr DY. He tells me that it would be unsafe to proceed with treatment without the option to provide blood product transfusion if required.
- 21. During the course of the hearing, I asked for further clarification from Dr SD about the risks for CX and his prognosis. She confirmed that:-
 - (i) There is no alternative to chemotherapy to treat this particular kind of lymphoma.
 - (ii) Chemotherapy cannot be delivered safely without the use of haemoglobin, platelets and white blood cells.
 - (iii) As far as she is aware, it is not possible to fraction any further the red blood cells needed for a transfusion.

- (iv) If CX is not treated now, it is likely that his cancerous tumour will continue to grow. It is likely to spread further and invade other life-supporting organs. Whilst it is currently a very indolent slow-growing tumour, there is a risk that, if left untreated, it could transform into a more aggressive form of cancer.
- (v) If left untreated, the cancer will make CX very unwell and it will cause his death.
- (vi) If there was a trial of chemotherapy unsupported by the use of blood products through transfusion, the effects on CX would in all likelihood be significant. It would make him very unwell. He would not be able to eat. He may well be unable to move on to the second planned stage of treatment at the second respondent's hospital. His life would be put at risk from bleeds into the gut and brain. Should he develop a septic disorder, his life would be put at risk as a result of that infection.

My conclusions

- 22. Whilst it is a finely balanced decision on the facts of this case, in my judgment CX is *Gillick* competent to make the decision as to whether or not to undergo the proposed treatment. I accept that he understands what will be involved in the various stages of the treatment even if he does not comprehend the detail of the medical science which underpins it. He is but 14 years old and does not have the wealth of professional experience shared by Drs SD, DY and those whom they have consulted in their collective search for the optimum treatment regime for his particular form of cancer. It is not without significance that there are no reports in the body of available medical case reports and literature of anyone having developed these two different forms of cancer.
- 23. He has questioned whether or not the treatment can go ahead with a trial of blood fractions as opposed to blood products. I am clear from the additional evidence I had from Dr SD (which I have set out in paragraph 21 above) that this is unlikely to be a viable option.
- 24. The rarity of CX's presentation is one of the fact specific aspects of this case which I have to take into account when looking at all the factors which fall to be considered in terms of his best interests. I have taken his religious views and those of his mother into account as another very important feature of this case. The tenets of his faith are extremely important to CX, as they are to his mother. However, they must be balanced against his clearly expressed wish to survive this illness. He has a mother who loves him dearly and it is difficult to imagine the agony of any mother who must stand by and watch a beloved child suffer as a result of such an illness as this. However, having listened to the doctors who are caring for him, I am satisfied that this is a situation where any increased suffering which may result from the proposed treatment is likely to lead to a very positive and commensurate benefit. I am equally satisfied on the basis of the evidence before the court that that ultimate benefit cannot be achieved without the use of full blood products. The current treatment plan has the unequivocal endorsement of the Guardian and the treating clinicians. All the medical

evidence points in one single direction: without this treatment, it is unlikely that CX will survive. I have already referred to the strong presumption in favour of taking all steps which are necessary to preserve life. I do not need in this case to rely on any presumption in relation to this particular patient. CX himself has given voice to his own human instinct to survive his illness. He is clearly a courageous individual who has faced his current predicament with both dignity and obvious strength of character. His doctors are in a position to treat him. Those very characteristics bode well for optimising the prospects of a successful outcome which will soon see him on the path to recovery.

- 25. Without the proposed treatment, I am satisfied that there is a very significant and material risk that the cancer from which CX suffers at the present time will spread and the probability is that his life will be put at risk as a result. Given his clear and unequivocal statement to the Guardian that he wishes to live and return to normal life as he has experienced it prior to his current diagnosis, I am left in no doubt that the anger and upset he may well feel as a result of the authorised imposition of any treatment which involves the use of blood products contrary to the tenets of his religious beliefs are likely to be eclipsed by the ultimate benefits of the proposed potentially life-saving treatment which has been planned for him.
- 26. Thus, notwithstanding my findings in relation to CX's *Gillick* competence and his ability to make decisions about many of the aspects of the treatment which is proposed, I have reached a clear conclusion that it is undoubtedly in his best interests to undergo the treatment which has been planned for him. I accept that to some extent the plan must be flexible and responsive to any clinical presentation which becomes apparent through its course. I am confident that CX is now in the best medical hands and that whatever support he needs will be provided by those charged with his care.
- 27. In the circumstances, I propose to make a declaration that it is both lawful and in CX's best interests to receive blood and blood products in the course of the proposed treatment plan. The applicant is authorised to commence treatment immediately in accordance with whatever final plan has been agreed in the context of a multi-disciplinary meeting which I understand was convened late yesterday. Given the views of both CX and his mother, I am confident that the Trust will consider all alternative forms of management which can be undertaken from time to time by reducing the use of blood products to the lowest level necessary to keep him safe. In that way, appropriate respect for the views of CX and his mother will be accommodated within the proposed treatment plan. However, in the event that those responsible for CX conclude that there is no reasonable alternative to the administration of blood and/or blood products, they will be at liberty to administer them without the consent of CX or his mother.

Order accordingly