JUDICIARY OF
ENGLAND AND WALES

Decision and short reasons to be released to the media in the case of Charlie Gard

This summary is issued to assist understanding of the court's decision handed down on Tuesday 11 April 2017. The full Judgment will be read out in court this afternoon and published at a later date.

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11 April 2017

Please note that the Judgment in this case is subject to the reporting restrictions orders that have already been made in order to protect the anonymity of the medical team and those that have given second opinions both here and abroad. In the event of any doubt as to the nature and scope of those reporting restrictions please obtain a copy of the orders made from any of the lawyers involved in this case.

I extend my thanks to those members of the press who have attended this hearing for their understanding of the sensitive issues that arise in this case and the need to protect the confidentiality of the medical staff involved both here and abroad. It has also been agreed, and I have so ordered, that the identity of Charlie's guardian should remain confidential.

Following discussions with counsel acting for Charlie's parents, it has been agreed that I shall give my decision with brief reasons now and then adjourn for a short time before I give my full Judgment. This note is intended to be a summary of the decision but any reporting of this case should be based on my full Judgment, shortly to be delivered in open court, subject to the aforementioned reporting restrictions.

This is the final hearing of an application made by the Great Ormond Street Hospital for Children NHS Foundation Trust pursuant to the inherent jurisdiction of the High Court in relation to Charles Gard (known to all as Charlie) who was born on 4 August 2016 and who is therefore just over eight months old. By their application dated 24 February 2017, the applicants ask the court to make the following orders:

1. that Charlie, by reason of his minority, lacks capacity to make decisions regarding his medical treatment;

2. that it is lawful and in Charlie's best interests for artificial ventilation to be withdrawn;

3. that it is lawful and in Charlie's best interests for his treating clinicians to provide him with palliative care only; and

4. that it is lawful and in Charlie's best interest not to undergo nucleoside therapy;

provided always that the measures and treatments adopted are the most compatible with maintaining Charlie's dignity.

Plainly, by reason of his age, it is not in issue that Charlie lacks capacity to make decisions regarding his medical treatment. Charlie has been represented throughout this hearing by his Guardian and by very experienced counsel. The parents have been represented by experienced and dedicated solicitors and counsel who have acted pro bono and I wish publicly to pay tribute to them for their excellent assistance to the court and, I am sure, to their clients. GOSH has been represented throughout by very experienced Leading Counsel.

Charlie's parents Constance Yates (Connie) and Chris Gard (Chris) oppose the other orders that are sought by the applicants.

The matter originally came before the court on the 3 March this year when I adjourned the proceedings so that Connie and Chris could file their evidence and, in particular, obtain evidence from the USA as to the treatment that might possibly be available for Charlie.

When Chris started his evidence he described himself as “Charlie’s proud father”. I am in no doubt at all that he and Connie are Charlie’s proud parents. The duty with which I am now charged is to decide, according to well laid down legal principles, what is in Charlie’s best interests. Some people may ask why the court has any function in this process; why can the parents not make this decision on their own? The answer is that, although the parents have parental responsibility, overriding control is vested in the court exercising its independent and objective judgment in the child’s best interests. The Great Ormond Street Hospital has made an application and it is my duty to rule on it, given that the parents and the hospital cannot agree on the best way forward.

The relevant legal principles which guide the exercise of my jurisdiction are well settled. It is important that I stress that I am not applying a subjective test, I am not saying what I would do in a given situation but I am applying the law. In *Wyatt v Portsmouth NHS Trust* reported at [2005] EWHC 117, the Court of Appeal set out what it referred to as the “intellectual milestones” for a judge making a decision of the kind with which I am faced today:

“In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child’s best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the child. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. The term “best interests” encompasses medical, emotional, and all other welfare issues.”

Charlie’s parents have, sadly but bravely, acknowledged and accepted that the quality of life that Charlie has at present is not worth sustaining, for he can only breathe through a ventilator and, although they believe that he has a sleep/wake cycle, and can recognise them and react to them when they are close, they realise that he cannot go on as he is, lying in bed, unable to move, fed through a tube, breathing through a machine. In my full Judgment I shall set out more details of his full medical condition.

All of Charlie's treating doctors at GOSH are agreed that Charlie has reached the stage where artificial ventilation should be withdrawn, that he should be given palliative care only and that he should be allowed to die peacefully and with dignity. Charlie has been served by the most experienced and sophisticated team that our excellent hospitals can offer. His case has also been considered by an expert team in Barcelona, which has reached the same conclusion. Charlie's condition is exceptionally rare and I am confident that I have had reports from around the world from those who know it as well as anyone can.

It seemed, at the outset of this hearing, that there might have been a lone voice in the USA that was offering what has been described in some reports as "pioneering treatment". Understandably, Charlie's parents have grasped that possibility, they have done all that they could possibly have done, they have very publicly raised funds. What parents would not do the same? But I have to say, having heard the evidence, that this case has never been about affordability, but about whether there is anything to be done for Charlie. At one stage GOSH got as far as deciding to apply for ethical permission to attempt nucleoside therapy, a treatment that has never been used on patients with this form of MDDS. But by the time that decision had been made, Charlie's condition had greatly worsened and the view of all here was that his epileptic encephalopathy was such that his brain damage was severe and irreversible, that treatment was potentially painful but incapable of achieving anything positive for him.

I was aware that I was to hear evidence from the doctor in the USA who was, reportedly, offering what had been referred to as pioneering treatment. Before he gave evidence, I encouraged the treating consultant at GOSH to speak with him, which she was able and willing to do. I am truly grateful to these experts for the time that they have given to this case. The outcome of that discussion is illuminating and the doctor in the USA said the following:

"Seeing the documents this morning has been very helpful. I can understand the opinions that he is so severely affected by encelopathy that any attempt at therapy would be futile. I agree that it is very unlikely that he will improve with that therapy. It is unlikely."

However, the US doctor made it clear that, were Charlie in the US, he would treat him if the parents so desired and could pay for it. As I have already said, funding in this case is not in issue. The US doctor also confirmed during this telephone conversation that he had never treated with nucleoside therapy anyone who had encephalopathy, therefore he was unable to indicate from any scientific basis whether a patient with encephalopathy would respond positively.

Charlie suffers from the RRM2B mutation of MDDS. No one in the world has ever treated this form of MDDS with nucleoside therapy, although patients with a different strain, TK2, have received nucleoside therapy, with some recorded benefit. In mouse models the benefit to TK2 patients was put at 4% of life expectancy. There is no evidence that nucleoside therapy can cross the blood/brain barrier, which it must do to treat RRM2B, although the US doctor expressed the hope that it might do so. There is unanimity among the experts from whom I have heard that nucleoside therapy cannot reverse structural brain damage. I dare say that medical science may benefit, objectively, from the experiment, but experimentation cannot be in <u>Charlie's</u> best interests unless there is a prospect of benefit for him.

The GOSH team believe that Charlie can probably experience pain, but is unable to react to it in a meaningful way. Their evidence was that being ventilated, being suctioned, living as Charlie does, are all capable of causing pain. Transporting Charlie to the USA would be problematic, but possible. Subjecting him to nucleoside therapy is unknown territory, for it has never even been tested even on mouse models, but it may (or may not) subject the patient to pain, possibly even to mutations. But if Charlie's damaged brain function cannot be improved, as all agree, then how can he be any better off than he is now, which is a condition that his parents believe should not be sustained?

It is with the heaviest of hearts, but with complete conviction for Charlie’s best interests, that I find it is in Charlie’s best interests that I accede to these applications and rule that GOSH may lawfully withdraw all treatment save for palliative care to permit Charlie to die with dignity.

I want to thank the team of experts and carers at GOSH, and others who cannot be named, for the extraordinary care that they have provide to this family. Most importantly of all, I want to thank Charlie’s parents for their brave and dignified campaign on his behalf, but more than anything to pay tribute to their absolute dedication to their wonderful boy, from the day that he was born.