

# SOLICITORS JOURNAL

## Treatment withdrawal: Should a child's parents or the court decide?

As news breaks that the Supreme Court will hear an appeal by Charlie Gard's parents, David Lawson examines the principles behind the best interests test

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Charlie Gard has a rare genetic mitochondrial illness affecting in particular his brain, muscles, and ability to breathe. In October 2016, within two months of being born, he was admitted to Great Ormond Street Hospital experiencing lethargy and shallow breathing.



In December 2016, Charlie's mother heard about a new treatment being administered to a child at a reputable medical centre in the US. Great Ormond Street contacted the US team and was told there was no direct evidence about the efficacy of this treatment for someone with Charlie's condition but 'theoretical and anecdotal evidence' that it might help.

In January 2017, an application was made to the ethics committee for the treatment to be trialled in the UK. However, during January a very serious deterioration of Charlie's condition led doctors to conclude that further treatment would be futile, only prolonging Charlie's suffering.

### **Best interests application**

Everyone reading this case is aware of the dedication of Charlie's parents and the desperately difficult situation as recorded by both the High Court and the Court of Appeal.

Charlie's parents raised over £1m so that he could be treated in the US. The disagreement between them and the hospital about whether to continue treatment and transfer Charlie abroad led to an application to the High Court to determine Charlie's best interests.

The resulting judgment opens with this simple question and answer: 'Some people may ask why the court has any function in this process, why can the parents not just make the decision for themselves? The answer is that, although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child's best interests.'

Following a traditional best interests analysis, Mr Justice Francis concluded that the consensus medical view was that treatment would be 'futile'. Declarations were made that treatment, other than palliative care, was not in Charlie's best interests.

The judge's question of parental authority was the basis of an appeal to the Court of Appeal. Charlie's parents argued that the court could not prevent them arranging treatment for Charlie in the US, particularly from a reputable medical team, and that the court had no role using declarations to block parental decision making unless the child was at risk of 'significant harm'.

### **Significant harm**

As a matter of first principle, there is a conceptual clarity to the judge's question, but in terms of statute law and case authority the appellants were on difficult ground. They argued that parents are in a privileged position of giving or withholding consent which could only be overridden if pursuit of their option would be likely to cause the child significant harm.

They relied on only one case as a previous example, *Re: Ashya King* [2014] EWHC 2964. That is a first instance decision, widely covered at the time, in which parents took their child out of hospital in the UK and then to Prague for proton therapy. The local authority used the family courts and a European arrest warrant to try to return the child to the UK. The court held that a local authority should not intervene unless the child might suffer significant harm.

Charlie's parents tried to use that case to import something akin to the threshold criterion that a child must be suffering or likely to suffer 'significant harm' before the state could intervene in parental decision making about medical treatment (see section 31 of the Children Act 1989).

## **Test not applicable**

In the Gard case, the Court of Appeal held that this test did not apply in medical treatment cases. If there was nothing to choose between the benefits and detriments of different treatment options, the court was likely to stand back and regard the parents' decision as determinative. Where there was a difference in the options, the court would look 'keenly' at viable options put forward by responsible parents.

The choice between those options would not be made because an approach was argued for by the local authority, by a hospital, or by the child's parents. The sole principle is the best interests of the child. That should be determined in the conventional manner well established in authorities in this area.

The judge at first instance found that the prospect of treatment having any benefit was 'as close to zero as makes no difference'. Everyone was agreed that maintaining Charlie's present life was not in his best interests. So the Court of Appeal was able to conclude that even if a significant harm test had to be applied, taking Charlie to the US for futile medical treatment met that test.

The court's ruling confirms that in medical treatment cases a traditional best interests analysis should continue to be applied. The starting point is a 'balance sheet' of factors for and against each course of action, recognising that some cases may come down to just one, or a few, fundamental points. The court looks at welfare in the widest sense – medical, social, and psychological – and from the patient's perspective. The question for the court is the best interests of the child.

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