

“Loving parents – not hospital administrators, not judges, not government officials – should control the treatment of their children.”

In Charlie Gard’s case, should the state decide?

By Phil Lawler

Behind the complicated medical and legal questions of the [Charlie Gard](http://www.catholicculture.org/news/headlines/index.cfm?storyid=32049) [http://www.catholicculture.org/news/headlines/index.cfm?storyid=32049] case, there stands one clear moral principle:

Loving parents – not hospital administrators, not judges, not government officials – should control the treatment of their children.

Should Charlie be removed from his life-support system? Would nucleoside therapy be a viable option? I don’t have an intelligent opinion on those questions. Neither do you – unless you happen to be an expert on Charlie’s case and the rare mitochondrial disease that afflicts him. But his parents are convinced that the experimental therapy is the best option, and in this case they are the experts.

Are there times when the best interests of the patient are served by ending active medical treatment and concentrating on palliative care, as the doctors at Greater Ormond Street Hospital have recommended in this case? Yes. But in this case the parents judge that their child’s interests could be served best by one last effort at treatment.

Are there times when the state must intervene, overriding the rights of parents, to protect a child’s welfare? Yes. But those extraordinary cases arise when irresponsible parents put their children in danger. In this case there is no evidence whatsoever that Charlie’s parents are irresponsible; quite the contrary. They are trying their best to keep their child alive.

Are there times when accepting a quick death might be more charitable than prolonging a patient’s suffering? Yes. But the doctors are not arguing that Charlie is in pain, nor have they demonstrated that his welfare would be at risk if he were transferred to another hospital for the therapy his parents want.

So why are administrators at Greater Ormond Street Hospital so determined to oppose the parents’ wishes? Why have British and European courts upheld the power of the administrators, over the rights of the parents? Even now, why are political leaders in the UK reluctant to intervene, telling American and Vatican officials that they cannot countermand a court order?

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There’s an important principle at stake here. The courts and the British establishment are basing their decisions on the assumption that the state – not the individual, much less the parents – should make decisions about medical care.

Why have hospital officials refused even to transfer Charlie to a hospice, where he could receive the same palliative care that they have prescribed? Is there any other plausible explanation for that heartless inflexibility, aside from their determination to enforce their decisions in preference to those of the child's parents?

From the perspective of the medical establishment, Charlie Gard is not a suitable candidate for experimental treatment. His prognosis is poor. Even if the treatment were successful, it is too late to reverse the serious brain damage that the disease has caused. At best Charlie will have very severe disabilities. The High Court applauded his parents for recognizing that "his present quality of life is one that is not worth sustaining."

But the question before the court did not involve sustaining Charlie's current condition; nobody was proposing to maintain the medical status quo. The question was whether or not to attempt treatment that might improve the patient's quality of life.

And what Charlie's parents have actually said is somewhat different from what the High Court suggested. His father testified that if the experimental treatment did not produce results, they would accept the inevitable and end the treatment. "After three months we would want to see improvement and, if there wasn't, we would let go. This is not the life we want for Charlie." There is no danger, then, that Charlie Gard would languish helplessly for years in a hospital bed.

Nor is there any danger, at this point, that care for Charlie Gard will be a burden on his family or his nation. His parents have raised enough money to cover the costs of nucleoside therapy, and at least two hospitals have offered free care anyway.

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The doctors of Greater Ormond Street doubt that nucleoside therapy would be useful in Charlie's case. Maybe they're right. Charlie's father concedes that possibility. But why not give it a try? An attempt at treatment would not be burdensome to Charlie, to his family, to the hospital, or to society.

Yes, it's a gamble. Charlie's parents – who know him and love him best – have determined that it's a risk worth taking.

Two statements from Catholic prelates

[\[http://www.catholicculture.org/news/headlines/index.cfm?storyid=31997\]](http://www.catholicculture.org/news/headlines/index.cfm?storyid=31997) – one from the Pontifical Academy for Life, the other from the bishops' conference of England and Wales – missed the point entirely by offering only expressions of sympathy for Charlie's parents without energetically defending their rights against the bureaucratic encroachment. (In fact, both statements sympathized with the courts and the hospital administrators as well, strongly suggesting that the parents should bow to the decisions of these authorities.) Even the later statement from **Pope Francis** [\[http://www.catholicculture.org/news/headlines/index.cfm?storyid=32007\]](http://www.catholicculture.org/news/headlines/index.cfm?storyid=32007), while it was a considerable improvement, still failed to address the central moral principle.

The Russian Orthodox Metropolitan Hilarion was more forthright, condemning the European Court of Human Rights for a “monstrous” decision that ignored the fundamental human rights of a helpless child and the parents who love him.

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