

Court battle over UK baby raises ethical conundrum

July 25 2017

A five-month [legal battle over the fate](#) of a terminally-ill British baby that drew the attention of Pope Francis and US President Donald Trump has also stoked an often angry debate about medical ethics and the courts.

Charlie Gard's parents waged a high-profile campaign with the help of [social media](#) and Britain's tabloids for him to receive experimental treatment in the United States, striking a chord worldwide.

They are now spending the last few days with their 11-month-old son before [life support](#) is withdrawn at a hospital in London after acknowledging in court on Monday that therapy could no longer help him.

"No-one wanted this outcome. No-one believes this outcome was in Charlie's best interests," said Julian Savulescu, director of the Uehiro Centre for Practical Ethics at the University of Oxford.

"There has got to be a better way."

Charlie was born on August 4 last year with a rare form of mitochondrial disease that causes [progressive muscle weakness](#) in the heart and other key organs and is only able to survive with life support.

His parents raised money to take their baby to the United States through crowdfunding but were prevented from doing so by the hospital and first

went to court in March to try and overturn that decision.

Their appeals went all the way to the Supreme Court but were turned down at all stages of the judicial process and judges at the European Court of Human Rights in Strasbourg refused to intervene.

Who should decide?

Charlie was due to be taken off life support before the Vatican intervened on July 2 with a statement in which Pope Francis expressed his support for the parents and said he hoped doctors would allow them to "care for their child until the end".

Trump offered his support the following day, saying in a tweet that he would be "delighted" to help.

A Vatican-run hospital in Rome and a US hospital then offered to treat Charlie and London's Great Ormond Street Hospital went to court to seek a ruling on whether to allow him to undergo experimental therapy.

There have also been small protests by supporters of Charlie's parents—a group calling itself "Charlie's Army"—outside Buckingham Palace and Downing Street calling for the hospital to listen to the parents.

Savulescu said social media had given greater power to parents to make their case heard.

"The question of who should decide is legitimate. Some people have wrongly concluded that these decisions should only be up to parents.

"But at the same time it is right that doctors, scientific experts and the courts should not be considered almighty, beyond question or account."

He said doctors should only activate legal mechanisms if "there is disagreement between the parents, or they are going to an unsafe place or they are very confident the parents' choice is unreasonable".

"The problem is not who has the power, it is how it is used and the need for robust, and humble, ethical deliberation," he added.

Charlie's case is far from the only [medical ethics](#) case to end up in court in Britain and elsewhere.

In France, the case of a man who was left severely brain damaged and quadriplegic as a result of a 2008 road accident has been in the courts since 2014.

Family members of Vincent Lambert are divided on whether to withdraw life support.

Role for mediation

Dominic Wilkinson, a consultant neonatologist and professor of medical ethics at Oxford University said court reviews in cases like Charlie Gard's was "not ideal".

"It is adversarial, costly and lengthy," he said.

"We need to find better ways to avoid cases of disagreement from coming to [court](#). There is an important role for mediation to help [parents](#) and doctors where they have reached an impasse."

But Ian Kennedy, emeritus professor at University College London said the courts must be respected.

"Parents cannot always be the ultimate arbiters of their children's

interests," he wrote in The Guardian.

"We are not in the realm of there being a right answer. We are in the realm of judgment, reasoned judgment, and we look to the courts to provide this."

Kennedy warned that campaigns against the courts were "increasingly a feature of modern discourse".

"It is one thing to comment on or criticise a particular decision. It is a very different thing to attack the institution of the courts."

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