

Judicial logic and illogical hope have clashed over Alfie Evans

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His case has captured the world's attention because of the dilemma it presents: who decides a child's fate?

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You won't have heard of Clarissa Tan but, had things worked out differently, you would have. Lured from her native Malaysia to work for *The Spectator* after winning our travel-writing prize, she was quickly republished in national newspapers, to great acclaim. But her career was abruptly halted by a colon cancer diagnosis – and the start of a medical and psychological journey familiar to millions. As treatment after treatment failed, her chance of survival fell from 30 to 10 per cent, then even lower. Yet right up until the end, she focused on that tiny chance of a cure. As did I.

Illogical, perhaps, but in such situations hope tends to replace logic – it is part of human nature. So it is with the parents of Alfie Evans, who managed to keep their hope alive in spite of everything. When he was born, almost two years ago, he was healthy and happy. But later he developed a squint, then stopped smiling.

A brain scan revealed an unexplained degenerative illness. When he caught pneumonia, at seven months, his parents were told to prepare for the worst – but he pulled through. When they were told his

brain condition was terminal, they refused to give up.

There are many NHS stories involving sloppiness or lack of attention. This isn't one of them. Alfie was seen by several internal and external experts including Professor Judith Cross, perhaps Britain's leading authority on child epilepsy. Nothing in his brain was working properly, she said, and his seizures are a consequence of that. The second opinions sought by his parents, by experts from Rome and Munich, did not dispute that the damage was irreparable. One described his state as "semi-vegetative", which, at least, made it highly unlikely that he was in pain. But even that could not be said for sure.

There are cases like this the world over, but what makes this so different is that Alfie's parents were not asking for the NHS to keep treating him. They wanted to take up an offer of alternative treatment in a hospital in Rome, an offer personally backed by the Pope and with the Italian government so keen that Alfie was granted Italian citizenship. Poland's president has offered his support and the American press has taken up a keen interest. The case has gone global not just because of the child's plight, but because of the modern dilemma it represents: who decides on the life of a child?

Under English law, it's quite clear: the "best interests" of the child are defined by the courts, not the parents. In this case, Mr Justice Hayden ruled that Alfie must "conclude his life" rather than risk a "burdensome" journey to Italy, adding that "nobody would wish Alfie to die in transit". The views of his parents were overruled. As were the views of the parents of Charlie Gard, a baby who died in

London last year after courts ruled he should not be transferred to New York for treatment.

What shocks so many overseas observers is that England's judges, rather than its parents, make such decisions. During Charlie's case, Ted Cruz, a one-time presidential contender, asked why "government should have power to decide who lives and dies". To other Americans, this is what happens when the government runs healthcare: power is taken out of the hands of the patients and the parents, and into those of the bureaucracy. Even power to decide the life of a child.

What makes it all the more emotive is that Alfie's parents, Tom Evans and Kate James, are Catholics who described their son as a "child of God". The offer of help in Rome came from the Vatican, and the offer of help in Munich from a doctor who says history has taught Germans that "there are some things you just don't do with handicapped children". This reference infuriated Mr Justice Hayden so much that he included it in the ruling. He has since taken the extraordinary step of describing the family's legal adviser (from the Christian Legal Centre) as "fanatical and deluded" – making it sound as if he has been joining the fray, rather than staying above it.

For those seeking a cultural war, there is plenty to fight about. But this is about the rights of parents, not religion versus science. Nor is it about the NHS system, because such cases happen even in America. In 2006, the Massachusetts Supreme Court ruled that Haleigh Poutre, 11, be removed from life support – in spite of the pleas of her stepfather – after her being in a vegetative state for months. She regained consciousness the day after the ruling,



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Such stories – of miracles, or near-miracles – often sustain those fighting against all the medical odds. A few months before she died, my friend Clarissa went to a clinic in Spain that offered an alternative treatment she didn't really believe in – but she argued that a 1 per cent chance at life was better than 100 per cent chance of death. She wrote a list that I still have: Advantages of my current situation. She found no fewer than 23. At the top: "There is more room in my life for hope."

In Alfie's case the strong human instinct – to pursue hope, against all odds – has collided with judicial logic. The chances of Alfie being given any significant help in Rome? Minuscule. But people still pursue long shots.

Alfie's dad, who left school age 16 to train as a plasterer, represented himself in court – making his case with such expertise and eloquence that the judge asked if someone had primed him with questions. Alfie's birth wasn't planned, and came when both his parents were in their late teens. But the force and power with which they have fought for him is nothing short of extraordinary, and is another reason that their story is being followed the world over.

In Britain, for all the case's complexities, this boils down to a simple question. And that is, if the NHS could do no more for Alfie, should his parents have had the right to take up the offer of treatment elsewhere? At one point, a medic proposed that his undiagnosed condition be called "Alfie's disease" in his honour. It would be better if the rights of parents in such tragic circumstances were to be protected by parliament, and the legislation called Alfie's Law.