

# Dominic Lawson

## Parents can love, but not protect: ask Alfie's mum



Woe betide any family that clashes with the British medico-legal system

Even if Alfie Evans had been a normal toddler, he would still have had no comprehension of the fact that the Polish president and the Italian government had been campaigning for him. But Alfie Evans had no comprehension of anything at all, an English judge having declared, with studied brutality, that his brain had “been wiped out ... [it] is almost entirely water”.

Last week Mr Justice Hayden denied Alfie's parents, Tom Evans and Kate James, their request to take their 23-month-old child from Alder Hey Children's Hospital to Italy after its removal of his ventilator: the government in Rome had given Alfie Italian citizenship, and the Eternal City's Bambino Gesù hospital had offered to take over his treatment.

His original judgment allowing doctors to remove life support is held to be the expert logic of the courts triumphing over the alleged irrationality of two young working-class Liverpool Catholic parents. Hayden was correct in noting that under English law the courts must give paramountcy to the “interests of the child”, rather than the wishes of its parents. But the ruling was not just cruel to those parents: it was not even logical on its own terms. It asserted both that subjecting Alfie to more treatment would cause him further unnecessary suffering and that he was, as the Alder Hey doctors asserted, effectively braindead and incapable of feeling anything, including pain. Both propositions could not simultaneously be true.

This is also the view of a distinguished doctor friend of mine, Rajesh Munglani, who happens to be Britain's leading consultant in the field of pain medicine. He told me he regards the court's decision over Alfie Evans to have been “wrong” and adds that the 2015 case *Montgomery v Lanarkshire Health Board* extends the requirement for doctors to take the wishes of patients into account, or, where children are involved, those of the parents.

Munglani had a particular personal interest in the 2014 case of Ashya King, a five-year-old boy whose parents removed him from Southampton General Hospital after it had refused their request to have his brain cancer treated abroad by proton beam therapy. The hospital – which declared this treatment to be worthless, although its own did not offer much hope – alerted the police to go after the Kings when they took their son out of the country, heading for Prague, which did provide proton beam therapy. The Munglani had gone with

their own daughter (who had just graduated from Oxford) to Florida for proton beam therapy to treat her sarcoma. She is now clear of cancer – as, in fact, is Ashya King. As Rajesh remarked to me: “If Ashya King's parents had followed the doctors' advice, their child would now be dead or more seriously brain-damaged. And my daughter would not be alive or as well today had it not been for this technology, which the NHS still does not provide.”

This is emphatically not an argument for parents to impose quacks on seriously ill children. But the NHS has an institutional antipathy to experimental forms of cancer treatment, even in cases where it knows its own methods hold no prospect of a lasting cure. I can't help thinking a system in which patients and their parents are not themselves paying (except compulsorily as taxpayers) encourages the attitude that they should keep quiet and be grateful for what they get.

Still, the vituperation directed at the staff of Alder Hey is unconscionable. They looked after Alfie to the very best of their ability, and must also have felt distress as his condition – the result of an inexplicable degenerative disorder that attacked the brain of an apparently healthy newborn – worsened. But for him to have ended up as, in effect, a prisoner until death of the state that had earlier removed his ventilation against his parents' wishes is no advertisement for the English medico-legal system. It's one thing to give up the medical fight for the child's life; quite another to say to the parents, “But, all the same, you can't take him away from us, either back home to die or to a foreign hospital prepared to treat him at its own expense.”

Even if such treatments are pointless – our courts had decided there was no further point in the existence of Alfie Evans – it offends against our entire idea of family to treat the feelings and wishes of loving parents as irrelevant. This love is not just the

indispensable basis of a good society. Maternal love is the most powerful force in the known universe. It demands more respect than this.

That truth is about to be put before the courts in another case, in which my wife is involved. With two other mothers whose adult children, like our younger daughter, have what nowadays is called “learning difficulties”, she is bringing a test case before the Court of Protection. As the law stands, the parents of such adults, whether in residential care or not, have no right to a decisive role in how their children are treated. The carers would be obliged to give the parents such a right if the mother or father were appointed by the courts to be their adult child's welfare deputy. But the current code stipulates that this can be agreed by courts only “in the most difficult cases”.

This crowdfunding legal test case, which will come before the Court of Protection probably in June, seeks to remove this requirement as set out in the code and simply rely on the Mental Capacity Act, which makes no mention of “the most difficult cases” but treats the idea of parental “deputyship” as normal. The case is being run by Alex Rook, a solicitor from Irwin Mitchell whose life's work is acting for families in such circumstances. He has heard enough from parents deeply distressed to discover, as he puts it, “that an official who has rarely met their child, or a social worker who has seen them for an hour, can make a life-altering decision – for example, involving medication – when the people who have known them for their entire life and understand them better than anyone are not consulted as they should have been under the act.”

Because these men and women reliant on social care are technically adults, the authorities tend to believe they should be fully independent of their parents. But the point is that while, on reaching the age of 18, they are adults under the law, people such as my daughter Domenica (who has Down's syndrome) remain as dependent as any child. Childlike, one might say.

I was going to add that parents of such adults should be accorded the same rights and respect as the state grants parents of little children. But then I thought of the poor, devoted parents of Alfie Evans, and realised that such respect doesn't even extend to them. No wonder the Poles and the Italians look at us with amazement bordering on disgust. [dominic.lawson@sunday-times.co.uk](mailto:dominic.lawson@sunday-times.co.uk)

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