

Charlie and Alfie. Should the law change?

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Funding: DW and JS were supported for this work by grants from the Wellcome trust WT106587/Z/14/Z, WT 104848/Z/14/Z.

Word count: 794 words

In the early hours of 28th April, 2018, 23-month old Alfie Evans died in Alder Hey hospital following a prolonged dispute over his medical care.¹ Alfie had a severe neurodegenerative disorder, and had been ventilated in intensive care for much of the preceding 16 months. His parents wanted life support to continue, but Alfie's doctors believed that this would be futile; in late February, the High Court ruled that life-sustaining treatment was not in Alfie's interests. Subsequently, a series of (unsuccessful) appeals were heard by the Court of Appeal, Supreme Court, and European Court of Human Rights.¹

The final stages of the dispute about treatment for Alfie were accompanied by intense national and international scrutiny. Many drew parallels with the case of Charlie Gard, less than a year earlier.² International commentators and politicians were critical of the UK health system and judiciary and its perceived interference in parental decision-making. At the height of the conflict, staff at Alder Hey hospital reported unprecedented levels of abuse.³

In the wake of the Evans case, there have been calls for changes to UK law. But what changes to law could or should be pursued? What would actually help?

Disagreements about potentially inappropriate medical treatment are not unique to the United Kingdom.⁴ Many jurisdictions have struggled to find satisfactory legal responses to the problem of so-called "medical futility".⁵ While the recent cases have been criticised, the UK approach compares favourably with others in its transparency, rigour and consistency.⁶

One option would be to respect parental autonomy – allowing parents to be the final decision makers about medical treatment. Such a solution would avoid legal disputes. However, it would also come at considerable cost. It would require health professionals to continue to provide treatment even where it would cause significant harm to the child. It would also, by consuming limited medical resources, compromise the ability of health professionals and the health system to provide beneficial treatment to other children and distribute resources fairly.⁷

A different solution would be to resolve disputes without recourse to court. A treatment tribunal model, as applied in Texas, applies an explicit process for assessment and arbitration in cases of potentially inappropriate treatment.⁸ This model has the advantage of potentially allowing timely decision-making and avoiding costly and protracted legal appeals.⁸ (In a forthcoming book, we argue that a modification of this model could help separate out important questions of limited resources from those relating to the interests of the patient).⁹ However, this due process model also has its critics who argue that it compromises patients' and families' legal rights.¹⁰ It would require substantive legal reform.

One question, debated in the Evans and Gard cases, is whether courts should reach decisions based on their view of what would be best for the child (the best interests standard) *or* based on whether parents' preferred treatment would risk significant harm to the child. Currently, courts apply the best interests test to medical treatment decisions. There are strong ethical arguments that decisions to overrule parents should be based on the second, more stringent question.¹¹ This may or may not have led to a different decision

in either case; it would make legal decisions about medical treatment consistent with the standard applied to other types of decision.

A simpler legislative response to these cases would be to promote ways to resolve conflict at an earlier stage. One option would be improved access to clinical ethics consultation. Such consultation can provide a consistent process for addressing conflicts. It can help identify the nature and source of disagreement. Where there is reasonable disagreement about what would be in a child's best interests, parents' wishes should be respected.¹² There is some evidence that provision of ethics consultation in intensive care can help address conflicts and reduce provision of non-beneficial treatment.¹³ In the UK, however, clinical ethics committees are available in only a minority of acute NHS trusts.

Another option would be to offer independent mediation. This has been proposed as a way to respond to disputes around treatment for children. It involves a neutral external facilitator who aims to help parties reach a negotiated resolution that they can both accept. After a pilot training program, paediatric staff reported greater ability to recognise nascent conflicts and to manage and de-escalate conflict.¹⁴

Paediatric medical care is, at its best, a partnership between professionals and families, working together to promote the wellbeing of children. These prolonged and painful disputes about treatment are devastating for families, and traumatic for the medical and nursing staff. There are no winners, only losers. There is a pressing need now for professionals to come together with families to explore and implement new constructive solutions to avoid, mitigate and resolve disagreements about treatment. That would be in the best interests of all children.

1. Who was Alfie Evans and what was the row over his treatment? *BBC News* 2018 28/04/2018.
2. Wilkinson D, Savulescu J. Hard lessons: learning from the Charlie Gard case. *J Med Ethics* 2018;(forthcoming)
3. Shepherd A. Anger as Alfie's Army protests outside Alder Hey. *BMJ* 2018;361:k1801. doi: 10.1136/bmj.k1801
4. White DB, Pope T. Medical futility and potentially inappropriate treatment. In: Youngner S, Arnold RM, eds. *The Oxford handbook of ethics at the end of life*. Oxford: Oxford University Press 2016.
5. Pope TM. Medical futility statutes: no safe harbor to unilaterally refuse life-sustaining treatment. *Tennessee Law Review* 2007;75(1):1-81.
6. Bosslet GT, Baker M, Pope TM. Reason-Giving and Medical Futility: Contrasting Legal and Social Discourse in the United States With the United Kingdom and Ontario, Canada. *Chest* 2016;150(3):714-21. doi: 10.1016/j.chest.2016.05.026

7. Wilkinson D, Petrou S, Savulescu J. Expensive care? Resource-based thresholds for potentially inappropriate treatment in intensive care. *Monash Bioeth Rev* 2018;(forthcoming)
8. Stewart C. Futility Determination as a Process: Problems with Medical Sovereignty, Legal Issues and the Strengths and Weakness of the Procedural Approach. *Journal of Bioethical Inquiry* 2011;8(2):155-63. doi: 10.1007/s11673-011-9297-z
9. Wilkinson D, Savulescu J. Ethics, conflict and medical treatment for children: from disagreement to dissensus: Elsevier 2018. (Forthcoming)
10. Truog RD. Counterpoint: The Texas advance directives act is ethically flawed: medical futility disputes must be resolved by a fair process. *Chest* 2009;136(4):968-71; discussion 71-3.
11. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics* 2004;25(4):243-64.
12. Wilkinson D, Truog R, Savulescu J. In Favour of Medical Dissensus: Why We Should Agree to Disagree About End-of-Life Decisions. *Bioethics* 2016;30(2):109-18. doi: 10.1111/bioe.12162 [published Online First: 2015/04/25]
13. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA* 2003;290(9):1166-72.
14. Forbat L, Simons J, Sayer C, et al. Training paediatric healthcare staff in recognising, understanding and managing conflict with patients and families: findings from a survey on immediate and 6-month impact. *Arch Dis Child* 2017;102(3):250-54. doi: 10.1136/archdischild-2016-310737