

Reforms for disagreements in the care of critically ill children

Response to the Nuffield Council on Bioethics

Call for evidence on disagreements in the care of critically ill children

About Christian Concern

Christian Concern, and its partner organisation the Christian Legal Centre, has supported the parents in some very high-profile recent cases where there was disagreement about the care of critically ill children. In particular, we were involved in the recent cases of [Archie Battersbee](#) in 2022, [Zainab Abbasi](#) in 2019, and [Alfie Evans](#) in 2018. Christian Concern therefore has a significant interest in the care of critically ill children and has invested considerable time and resources to the subject. As well as providing legal support, Christian Concern has been active in the media explaining the issues and campaigning for reforms to the process for removal of life support for Children.

Background

The case of Archie Battersbee captured the attention of the nation last year as parents everywhere sympathised with the plight of Archie's mother. After a tragic accident on 7 April 2022, 12-year-old Archie Battersbee was left in a critical condition. He was initially given 24 hours to live. Two days later, the doctors said he was 'brain dead' and invited the family to come and say goodbye and to discuss organ donation. Later the Court of Appeal expressly overturned the declaration that he was brain dead. Previously Archie had been declared dead by the courts on the 'balance of probabilities.' This is a very concerning concept, and this declaration of death was also overturned on appeal. The courts then focussed on whether it was in Archie's 'best interests' to die. They argued that although Archie was not in pain, his dignity required a certain death at a certain time. It is unclear why a specified death is more dignified than letting matters run their natural course. Finally on 6 August at 12:15pm, four months after initially being given 24 hours to live, Archie Battersbee's life support was removed, and he died.

There have been several other similar high-profile cases of children who have had life sustaining treatment removed against the parents' wishes. These include: [Charlie Gard](#), [Alfie Evans](#), [Isaiah Hastrup](#), [Tafida Rageeb](#), and [Pippa Knight](#). On average there are 5 or 6 such cases of withdrawing life-sustaining treatment per year. About half of them remain completely secret, with no published judgment in the end. What these cases highlight is the urgent need for legal reform in a number of areas. Here we propose several reforms that are not difficult to implement, and which would significantly help reduce conflict in such cases.

Mandatory mediation

In theory, mediation is compulsory before commencing end-of-life proceedings (Great Ormond Street Hospital v Yates and Gard [2017] EWHC 1909 (Fam), para 20). However, in the case of Archie Battersbee, the NHS Trust repeatedly refused to engage in mediation with the family and the Court paid no attention to that. We therefore propose that the Court should be required to refuse permission to make the

application to withdraw life-sustaining treatment unless it is satisfied that the family was offered genuine mediation, and if the offer was accepted, that the Trust engaged in mediation in good faith. An assertion that the family refuse to engage in mediation must be proven by a written waiver of the right to mediation in a standard form, where the process is properly explained in writing, and the parents have signed to confirm that they understand the process and do not wish to engage in mediation. Subsequently, if at any stage of the proceedings the parents change their mind, they should have an automatic right for the court proceedings to be stayed for at least one month, while mediation service will be provided to the parties. The Trust would be subject to the same obligation to engage in mediation in good faith, otherwise the stay will not be lifted.

Mandatory consideration and approval by the Ethics Committee

In *GOSH v MX* [2020] EWHC 1958 (Fam), paras 21-23, and in *Re AA* [2014] EWHC 4861 (Fam), the Court has emphasised (a) the importance of the proceedings of the Hospital's own Ethics Committee, and (b) the effective participation of the family in those proceedings. In Archie's case, however, the Trust pursued a premature application without completing the Ethics Committee process. The court should be required to refuse permission to make the application until and unless there is proper approval by the Ethics Committee. Ethics Committees should be put on statutory footing and be required to guarantee the family's effective participation.

Minimum of 6 months' record of continuous care for the child as a precondition for applying to withdraw treatment

The assumption in cases of this kind is that the application represents a genuine professional view of clinicians who have cared for the child for a reasonably long time. That assumption is often unjustified. Hence is the need for a formal requirement of locus standi to make the application.

In a system where the applications are made by large corporate bodies, it is almost inevitable that NHS Trusts would grow a sub-strata of managers and clinicians who specialise in successfully pursuing such applications and getting hopeless cases resolved efficiently. This should not be allowed to happen. Clinicians who have a sufficiently long record of looking after a particular child should be required to take the lead in persuading the family, and ultimately the Court, that no stone has been left unturned to save the child.

Adequate notice to the family

The standard practice is for the application to be served on the family with first directions the following morning or within 48 hours, and final hearing within a couple of weeks. After the Trust has had all the time it wants to prepare the application, the family is rushed through the proceedings at a breakneck speed. This places unacceptable pressure on the family. The law should be reformed so that families are entitled to the same time limits as defendants in civil proceedings. This means the family should be given at least 14 days to acknowledge the service of the proceedings, and 28 days to provide a detailed response. Adequate time following the directions hearing should be given to prepare evidence. Prior to issuing proceedings, the Applicant should be required to comply with pre-action protocol by engaging in pre-action correspondence with the family to identify issues and to explore the possibility of resolving the dispute using Alternative Dispute Resolution rather than litigation.

Right to legal aid

Currently, even when it is a matter of life and death, there is no automatic right to legal aid for the family in cases of this kind. The entitlement to legal aid is 'means-tested', with wholly unrealistic threshold level

of income (disposable income just over £800 per month) making people ineligible to legal aid. This is manifestly unjust as has been widely recognised. The family should have an automatic right to legal aid with minimal formality, and any delay should give the family an automatic right to extend the time of proceedings.

Right to instruct medical experts

Currently, the family has no right to instruct medical experts of its own without permission from the Court, and until the Court grants permission to instruct, it is unlawful to share any information about the case with an expert. Given the unreasonable speed of proceedings, Courts often refuse to give permission unless it is proven that the family's expert's view will be different to that of the Trust's clinicians. This cannot be proven without the expert seeing the medical records, which cannot be shared with the expert without the Court's permission. This is a vicious circle that needs to be broken.

We propose that the family should have an automatic right to instruct its own experts, to share information with them, and to adduce their evidence, subject only to the requirement that the evidence is relevant.

Right to choose alternative provider of treatment/care

In several cases of this kind, there have been orders effectively prohibiting the parents from taking the child to a different hospital which is prepared to offer life-sustaining treatment at no additional cost to the NHS. In the case of Archie Battersbee, the parents were refused permission to take him to a hospice for end-of-life care. In the case of Alfie Evans, the parents were refused permission to accept an offer of care from Italy after the Italian government granted Italian citizenship to Alfie. An air ambulance was waiting outside the hospital ready to take Alfie to hospital in Italy at no cost to the NHS, yet this offer was refused by the Court.

The parents should have the right to seek an alternative provider of treatment or care. Once this right has been exercised, the previous clinical team should immediately lose standing to pursue its legal application.

Guarantee of open justice

Court hearings in cases of this kind lack the transparency required for open justice. Hidden proceedings only increase the common perception that abuses are being carried out with no opportunity for public scrutiny. All hearings in cases involving withdrawal of life-sustaining treatment should take place in open court. The extent to which the Court is able to impose reporting restrictions should be regulated. The press should be able to report on all proceedings subject to anonymity if, and only if, it is requested by the family.

Incorporate the UN Convention on the Rights of Persons with Disabilities into law

In Archie's case, the Court of Appeal refused to comply with interim measures granted by the [UN Convention on the Rights of Persons with Disabilities](#) (UN CRPD). It refused to give the UN Committee any time to consider the parents' complaint under the Convention. This put the UK in breach of its international law obligations under Article 4 of the Optional Protocol. It meant that the Court protected its decision from scrutiny by an authoritative international human rights body under the process to which the UK had voluntarily subscribed.

The UN Disability Convention requires the complainant to exhaust all domestic remedies before being able to complain to the UN Committee. If then the court refuses to let the UN Committee scrutinise the

decision, then then the Committee is never able to intervene in time to save someone's life. Meaningful compliance with the UN Convention means that a requirement to comply with the interim measures of the UN CRPD should be incorporated into domestic legislation.

Conclusion

As it stands the process for obtaining permission to withdraw life-sustaining treatment for children is far too rushed and fraught with injustices against the parents. The legal reforms proposed here would clearly slow down the process, make system fairer, and improve justice. We hope that the Nuffield Council on Bioethics will recommend each of these reforms to the government.