

# Nuffield Council on Bioethics

## Call for evidence: Independent review of disagreements in the care of critically ill children in England.

A response from the **Christian Medical Fellowship**.

### Introduction

The Christian Medical Fellowship (CMF) is an association of about 5,000 UK doctors, medical students, nurses, and midwives that exists to equip its members to live and work for Jesus Christ. We welcome this initiative from the Nuffield Council on Bioethics (NCoB) and the opportunity to contribute to it. Many of our members work in hospitals, including a number in paediatrics, neurology, neurorehabilitation, and hospice care. Tragic and complex cases like those of Charlie Gard and Archie Battersbee have prompted much discussion between us. They raise profound and troubling questions about the power of medical technology, the duties and responsibilities of doctors and parents, and the role of the law courts, as well as the impact of global media coverage and social media campaigns. We hope our observations will be of some help to reviewers.

### Communication issues

Nearly all dilemmas of medical ethics start with human pain. Our first response must be one of empathy. Whether we are professionals or spectators, we must try to enter into the pain – to recognise and acknowledge the distress and desolation of parents who weep and struggle and pray for healing for their children. Parents need to be confident that doctors are really listening, empathising, and seeking to understand their concerns and their goals for their child. When confronted with parents who do not agree, health professionals need to respond with compassion, flexibility, and preparedness to compromise.

All agree that the best approach to these profound dilemmas is one of collaboration. The health professionals and the parents need to develop a deep and effective partnership in which together they can work out what is best for the child. In most cases, trust and mutual respect between professionals and parents can be earned, developed and nurtured, without recourse to mediation.

But not always. Many forces conspire to corrode confidence and esteem between strangers. We are in a popular climate that increasingly distrusts experts and that celebrates the power of raw emotion and instincts rather than carefully assessed and scrutinised evidence. Large healthcare teams and shift-working threaten the continuity of care and weaken familiarity and friendship in the intensive care unit.

Unfortunately, the intense scrutiny of the 24-hour news cycle and the social media campaigns do not assist the process. Dedicated and caring hospital staff have been subjected to a barrage of abuse, hate mail, and even death threats. Nurses have been abused in the streets and families have been harassed whilst visiting their children in hospitals.

Confidentiality between patients and doctors has always been a bedrock principle of medical ethics. For 2000 years medics have known of the unintended harms to patients when privacy is breached.

In this new age of social media, when intimate medical details and discussions between doctors and parents are broadcast to the world, strange, unintended, and sometimes violent forces may be unleashed.

Collaboration depends on trust and mutual respect. A helpful concept is the expert-expert relationship. Health professionals are experts in the diagnosis and prognosis of diseases and the medical treatments that are available. But parents, too, are experts – in their family history and background, in their personal concerns, goals, and philosophy of life. And collaboration between experts can only work if there is openness, respect, and trust. Sadly, in both the cases quoted above – those of Charlie Gard and Archie Battersbee - that essential trust broke down.

In Archie's case, it seems the hospital quickly formed the view, based on initial neurological tests, that he had suffered a 'non-survivable' brain injury. Just three days after admission, when the family was still wrestling to come to terms with the situation, they were understandably upset when a consultant approached them about Archie becoming a deceased organ donor. At that time, they were still weighing up the risks of brain stem testing for Archie and were far from ready to accept the inevitability of his death. It is all too easy for those who work in emergency care settings, and who have become to some extent inured to the emotional intensity of that environment, to forget how it is for those who find themselves in a completely foreign environment and in turmoil over their critically sick child.

Brain death is a difficult concept even for medically qualified professionals to fully comprehend. When people are convinced that death occurs only when the heart stops beating, it takes much time and patience on the part of hospital staff to allow parents to accept that, although their child's heart may be beating and the child is warm and pink, they can still be clinically dead.

In Archie's case, therefore, the seeds of mistrust were sown early on and became the lens through which, increasingly, the family viewed the actions of the clinicians. At one point, Archie's mother became convinced the hospital was deliberately starving her son. Little wonder, then, that when the family had apparently been shown cropped photocopies of the MRI scans from which Archie's name and details had been removed, they were suspicious that the scans were those of someone else. Mrs Justice Arbuthnot, in her kind and thoughtful judgment, commented on how these *'issues raised show clearly the lack of trust the family has in the very experienced clinicians caring for Archie'*. Nevertheless, she found *'no reason to doubt'* that the three main clinicians treating Archie wanted *'what is best for him'*.

In this case, the breakdown of the family's trust in the motivation of the clinical team, coupled with the inability to perform the standard tests to confirm brain stem death, led inevitably to the involvement of the Courts. But with mutual understanding and better communication from the start, this might well have been avoided. The four-month period between Archie's admission to hospital and the date of his death would have been shortened, the delays and expense of repeated court hearings avoided, and the media frenzy and social media campaigns never launched.

### Differing Perspectives

The definition of what constitutes 'a life worth living' depends on one's beliefs and values. Differing perspectives between medical staff and parents over this question can contribute to conflict between them. False assumptions and/or perceived lack of respect for sincerely held beliefs undermine trust. Communication suffers. And the media are quick to represent a misunderstanding as a deliberate offense, which serves only to widen rifts and polarise public opinion.

By and large, the medical model in the UK is agnostic about faith, though individual healthcare professionals may embrace personal convictions rooted in religious convictions. Some parents of critically ill children will have an active faith that informs their view of the value of human life. Other parents will say that their child believes even if they, as parents, do not. In crises, many people who would not describe themselves as 'believers' nonetheless pray for divine intervention and may reach out to hospital chaplains.

At CMF, we believe that every human life has intrinsic value because we have been created in the image of God. The idea that there might be a 'life not worth living,' based on disability, ill health or loss of function, is unacceptable. Treatment given or withheld with the intention of shortening a life perceived as 'not worth living' is thus, in our view, unethical. Similarly, pressure on a staff member to participate in a treatment plan that would cause harm to their sense of moral integrity, would also be unethical. A society might therefore be measured by the investment of care and resources it lavishes upon those least able to contribute to it.

This is not to say that we believe life should be maintained 'at all costs.' There is such a thing as treatment that is futile and when it is clear that all hope of recovery has gone, then death should not be prolonged by artificial means. When biotechnology has progressed to the point where a person who is effectively dead can be kept alive almost indefinitely (and appear to a grieving parent as being merely unconscious – pulse, pink, warm, etc), then technology can become a 'monster' that prolongs suffering without the prospect of benefit.

Personally held faith will rightly cause parents not to agree to medical advice to 'switch off the machines' if there is any hope of recovery over time. They will not be persuaded by prognostications that their child, even if they did recover, would be a 'vegetable,' that it would be 'kinder' to end their life, etc. Medical professionals must take account of the view, held by many, that life is 'sacred' and cannot be defined by so-called 'quality' assessments. Disagreements may be avoided if religious leaders are invited to take part in discussions around 'best interests' care.

The question of when a person is dead is difficult to answer, even today. Proving brainstem death requires very significant clinical skills, with monitoring of small changes over time, and careful interpretation of tests and scans that may be ambiguous around the time of death. The preservation of organs for transplantation further complicates the process. It can take time and patience to explain to a distressed parent that their child is truly dead but being kept seemingly alive to optimise the prospects of a successful transplant. Certain faiths are opposed to removing organs from the dead; some traditions follow strict procedures in honouring the dead. Such a 'waste' of organs can seem anathema to some healthcare professionals. The scope for inadvertently causing offense is wide; education, understanding and sensitivity are at a premium.

### Feelings of Powerlessness

From the parents' perspective, there is a massive power gradient in favour of the medical staff. Parents are in a foreign environment, without easy access to wider relatives and friends; even just finding their way around can be confusing. Staff know the place like the back of their hand, know where to go for a bit of peace and quiet reflection, and are surrounded by colleagues.

In most cases, parents have no choice about which hospital they go to. They may have heard negative stories about the hospital on the grapevine (good stories seldom get retold). They are putting their critically ill child into the hands of complete strangers. Whilst still reeling, they may

receive lots of information to absorb, forms to sign, permissions to give. Conversations about their child are happening all about them, often using words they don't understand; people are moving this way and that to institute observations, investigations, monitoring etc. They are often the last people 'in the know.' They inevitably feel excluded. They need to feel they are partners with the staff in the care of their child, not observers only. Providing parents with a trusted and appropriately trained healthcare professional as a central point of communication can only help, and we enthusiastically support this suggestion. (Likewise, *'exploring ways in which those parents who want to can be more involved in discussions and decisions about their critically ill child, including having access to their child's medical records and reliable research findings'* might be helpful for some parents for whom greater understanding is reassuring and empowering.)

It takes time and understanding to explain the implications of information given. Time to gain insight into this family's values, hopes and dreams. The lack of continuity in care means that these parents may just be getting to know one of two staff members, and to trust them, when the staff changes shift or rota, and the parents have to get used to new faces.

The whole experience says to parents 'You're powerless in this situation.' It takes intentional action on the part of healthcare staff to see the family, not just the sick or injured child, as their 'patients' and to care for them accordingly. We agree that training in 'the avoidance and management of conflict' should be widely available and recommended for paediatric healthcare staff.

That sense of powerlessness is only exaggerated if the courts get involved. It's another new environment and a rather intimidating one at that. The parents rarely get to speak unless a kind judge visits them beforehand. Their child's interests are handled by an appointed guardian, normally unknown to them. Press and other media reporters are looking for a story and may invite parents to assume the role of victims.

Mediation clearly has a part to play, and hopefully can prevent things from ever reaching the stage where matters are taken to court. Early involvement of mediators, before trust is completely broken down, is essential.

Hospital staff may also experience a sense of powerlessness if matters do go to court. Almost always there is a long delay. Generally, staff are not allowed to talk to the press and cannot thereby limit misinformation. Sadly, they may not experience understanding and support from their employers. A recent Court of Appeal judgment ([2023] EWCA Civ 331) ended life-long anonymity protection for doctors in medical cases including controversial end-of-life scenarios. Decisions made around end-of-life care for critically ill children are nuanced. Even trained professionals may struggle to grasp their complexities, let alone newspaper editors and online platform gatekeepers. Doctors can be tried and found guilty in the 'court' of (ill-informed) public opinion long before cases reach the law courts.

In addition, *'exploring how healthcare professionals can be better supported to provide commentary to journalists when disputes about the care of critically ill children not under their care reach the news'* sounds like a worthwhile endeavour.

In our opinion, insufficient weight has been given to the wishes of parents in some recent situations where there has been disagreement with medical staff over the child's best interests. If parents wish to take their child to another hospital, even if that would involve an overseas trip, or if they wish to try the benefits of experimental treatments, against the advice of the treating physicians, then we believe that parents should generally be permitted to do so unless there are overriding reasons why it would be harmful to the child. Of course, this assumes that the receiving institution is able and

willing to provide the relevant care, and that NHS funds will not be drawn upon. The risks of possible harm associated with moving their child and exposing him or her to experimental treatment must be carefully explained (as far as they can be known) to parents, but the final decision should be theirs, assuming capacity. In the event of a tragic outcome, the releasing hospital and medical staff should not be culpable. Parents must understand that the responsibility rests with them.

### Delays in seeking help

Children's palliative care specialists are trained in a more holistic approach to family care and communication. It is tragically the case that often they are only involved when situations are 'terminal' - when the child is expected to die within hours or just a few days. Earlier referral and engagement could improve matters considerably. For this to be possible, access to children's palliative care services in all areas of the UK would need to be improved and we wholeheartedly support this goal.

It is also the case that many UK neonatal units do not have access to psychosocial support for families. This, too, should be addressed in an effort to improve family care, prevent the breakdown of trust between families and hospital staff, and reduce the number of cases ending up in the law courts.

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